DOCUMENT RESUME

ED 384 168 EC 304 004

AUTHOR	Klein, Stanley, Ed.
TITLE	Exceptional Parent. Volume 24, Numbers 1-12.
REPORT NO	ISSN-0046-9157
PUB DATE	94
NOTE	942p.
AVAILABLE FROM	Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146-5005.
PUB TYPE	Collected Works - Serials (022)
JOURNAL CIT	Exceptional Parent; v24 n1-12 Jan-Dec 1994
EDRS PRICE	MF06/PC38 Plus Postage.
DESCRIPTORS	Adolescents; Assistive Devices (for Disabled); *Child Rearing; Children; *Disabilities; Early Intervention; Educational Needs; Elementary Secondary Education; Health; *Parent Child Relationship; Physical Mobility; Recreational Activities; Religion; Summer Programs; Technological Advancement; Telecommunications; Toys; Young Adults

ABSTRACT

These 12 issues of "Exceptional Parent" present a variety of articles and other information relevant to parents of children with disabilities. The January issue provides an annual directory of national organizations, associations, products, and services. Other monthly issues each have several articles relating to a particular theme, including: (1) early intervention, (2) mobility, (3) summer activities, (4) recreational activities and services, (5) telecommunications, (6) teenagers and young adults, (7) health, (8) education, (9) toys, (10) technology, and (11) religion. Additional monthly features include columns providing parent-to-parent suggestions, suggested resources, personal narratives of parents, a directory of advertisers, a calendar of activities, and reviews of new products and books. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 384 168

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☐ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Exceptional Parent

Volume 24, Numbers 1-12

January- December 1994

BEST COPY AVAILABLE

PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

S.D. Klein

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

10270

JANUARY 1994

$19.95

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

THE EXCEPTIONAL PARENT 1994 RESOURCE GUIDE

DIRECTORIES OF NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS & SERVICES

0096********** 5-DIGIT 22091
A 4006066 - EXP 57
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1589

3

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford and Lincoln-Mercury Divisions

Circle #30

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

January 1994 Volume 24 Issue 1

5 National Information and Advocacy Resources

11 National Resources for Specific Disabilities and Conditions

25 Parent Training and Information Centers

31 Parent to Parent Programs

43 Alliance for Technology Access Centers

49 State Assistive Technology Programs

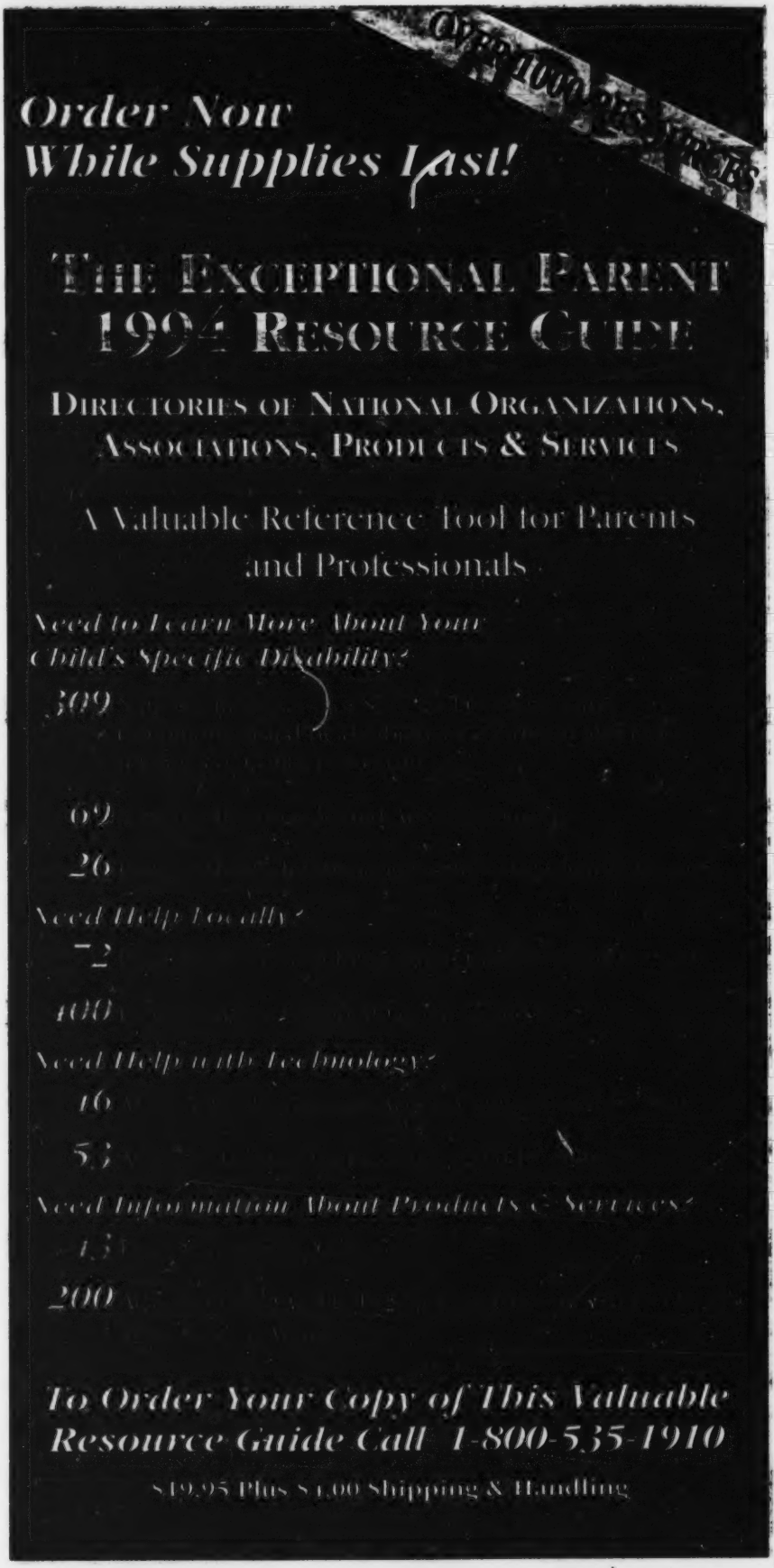
55 Federal Agencies

57 Federal Health Information Centers and Clearinghouses

59 1993 Exceptional Parent Topical Index

67 Directory of Products and Services

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, libraries, schools and agencies. Canada, add $6 per year in U.S. funds for additional postage. Latin America and other foreign countries add $9 per year in U.S. funds for additional postage. **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.



EXCEPTIONAL PARENT
Parenting Your Child With A Disability

Editor in Chief
Stanley D. Klein, Ph.D.
Professor of Psychology, New England College of Optometry

Assistant Editor
Kim Schive

Editorial Staff
Andrew M. Bissaro
Valerie Steele

Editorial Interns
Andrew N. Rhein
Annabel Tan

Consulting Editor
Maxwell J. Schleifer, Ph.D.

Editorial Office
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Phone (617) 730-5800
Fax (617) 730-8742

President and Publisher
Joseph M. Valenzano, Jr.

Vice President Marketing
Terri M. Sutera

Director, Organizational Relationships
R.K. Hopkins, Jr.

Director, Manufacturing
Lawrence Qualiano

Director, Distribution
Fred Ballerino

Finance Manager
Roy Whitaker

Publishing Office
120 State Street
Hackensack, NJ 07601
Phone (201) 489-0871
Fax (201) 489-1240

Art Director
Charles A. Horn

Assistant Art Director
Donna R. Hunter

Creative and Production
Morris/Weber & Associates, Inc.
Clifton, NJ
Phone (201) 478-2300
Fax (201) 478-2963

Color Separation/Film Preparation
Plate Masters Inc.
Carlstadt, NJ 07072
Phone (201) 935-7555
Fax (201) 935-7553

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 65

BPA International Consumer Magazine Membership Applied for August 1993

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

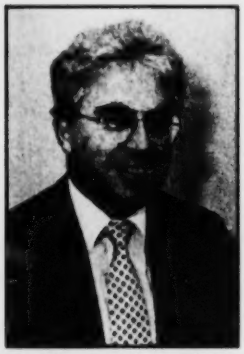
For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

MYDESC™
The Custom Desktop

1-800-4-MYDESC

Rhamdec, Inc. 7176 Ellis Street, Mountain View, CA 94043-2240 • MYDESC is a trademark of Rhamdec, Inc.

EDITOR'S DESK



Stanley D. Klein Ph.D.

Happy New Year and welcome to our first monthly issue of 1994—a special Resource Directory that will be useful all year. While some of these directories have appeared in previous issues of *Exceptional Parent*, most have been greatly expanded and enhanced since last published. In addition, we have made an unprecedented effort to verify addresses and phone numbers and to add "800" numbers, TDD and fax lines, and even computer bulletin board addresses when available.

National Resources

In an effort to organize our listings of national organizations and resources, we have created two distinct directories: National Information and Advocacy Resources and National Resources for Specific Disabilities and Conditions.

The Information and Advocacy directory lists groups focusing on issues of concern to many families of children with disabilities—regardless of their children's specific diagnosis. This is the place to find answers to questions about education, employment, health care, independent living and more.

The Specific Disabilities directory—the most extensive we have published—lists more than 300 sources of support and information on specific conditions. For the first time, we have provided cross-references between disability categories to enable readers to find all relevant resources for a particular disability. We hope that this new approach will alleviate confusion over terminology differences while helping parents obtain information on related conditions that may be useful in understanding an individual child.

The federal government can also serve as a valuable national information resource. Accordingly, this issue lists two directories of federally-funded resources for parents and professionals: Federal Agencies and Federal Health Information Centers and Clearinghouses.

Resources Close to Home

Exceptional Parent magazine was founded because all parents of children with disabilities have similar needs for information and support. The federal government established Parent Training and Information Centers (PTIs) for much the same reason—to reach out to parents of children with disabilities and special health care needs in local communities, and to work to improve opportunities for all children. Readers who need information about available programs and services, or who just want to network with other parents, can contact the nearest PTI from among more than 70 listed in this issue's directory.

Parent to Parent Programs have evolved in local communities as a way to provide one-to-one emotional and informational support to parents of newly diagnosed children with special needs. With the help of the Beach Center on Families and Disabilities at the University of Kansas, we are pleased to provide a state-by-state listing of local Parent to Parent groups.

Assistive technology has enabled many children with disabilities to interact with the world in new and exciting ways. In recognition of the importance of technology in the lives of many of our readers, this issue offers two state-by-state listings of assistive technology resources: State Assistive Technology Programs and Alliance for Technology Access Centers.

Products and Services

Parents and professionals constantly tell us about finding solutions to challenging problems through a product or service advertised in *Exceptional Parent*. For this special issue of the magazine, we have compiled a Products and Services Directory in which many companies and organizations have purchased listings. This directory can be used as a guide to the many specialized products and services available. In addition, a Free Product & Service Information card is available to parents and professionals who would like to obtain more detailed information from participating advertisers.

More resources

This issue also includes a complete topical index of all articles published in 1993.

Beginning with this issue, we are pleased to present another resource for parents and professionals—the *Exceptional Parent Library*. This service offers books on a variety of useful and interesting topics. We welcome suggestions about additional books we should include as this book service continues to expand.

National Information & Advocacy Resources

These national organizations are information and advocacy resources for parents and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on specific areas of concern to the families of children and adolescents with disabilities.

GENERAL

Access/Abilities
P.O. Box 458
Mill Valley, CA 94942
(415) 388-3250
(415) 383-8718 (FAX)

Alliance of Genetic Support Groups
35 Wisconsin Cir, Ste 440
Chevy Chase, MD 20815-7015
(800) 336-4363
(301) 652-5553
(301) 654-0171 (FAX)

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton St, Ste 410
Silver Spring, MD 20910
(301) 588-8252
(301) 588-2842 (FAX)

Any Baby Can
5410 Fredericksburg Rd, Ste 104
San Antonio, TX 78229
(210) 377-0222
(210) 377-0497 (FAX)

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
(202) 662-3520 (FAX)

Council for Exceptional Children
1920 Association Dr
Reston, VA 22091-1589
(703) 620-3660 (Voice/TDD)
(703) 264-9494 (FAX)

DIRECT LINK for the disABLED
PO Box 1036
Solvang, CA 93464
(805) 688-1603 (Voice/TDD)
(805) 686-5285 (FAX)

Learning How
PO Box 35481
Charlotte, NC 28235-5481
(704) 376-4735 (Voice/FAX)

MUMS (Mothers United for Moral Support)
c/o Julie Gordon
150 Custer St
Green Bay, WI 54301
(414) 336-5333
(414) 339-0995 (FAX)

National Center for Youth with Disabilities
University of Minnesota
Box 721—UMHC
420 Delaware St SE
Minneapolis, MN 55455
(800) 333-6293
(612) 626-2825
(612) 624-3939 (TDD)
(612) 626-2134 (FAX)

National Easter Seals Society
230 W Monroe
Chicago, IL 60606
(800) 221-6827
(312) 726-6200
(312) 726-4258 (TDD)
(312) 726-1494 (FAX)

National Information Center for Children and Youth with Disabilities (NICHCY)
PO Box 1492
Washington, DC 20013
(202) 416-0300
(202) 416-0318 (TDD)
(202) 416-0312 (FAX)

National Organization on Disability
910 16th St NW, Ste 600
Washington, DC 20006
(800) 248-2253
(202) 293-5960
(202) 293-5968 (TDD)
(202) 293-7999 (FAX)

National Vaccine Information Center Dissatisfied Parents Together
512 W Maple Ave, #206
Vienna, VA 22180
(703) 938-3783
(703) 938-5768 (FAX)

NPND (National Parent Network on Disabilities)
1600 Prince St, Suite 115
Alexandria, VA 22314
(703) 684-6763 (Voice/TDD)
(703) 836-1232 (FAX)

STOMP (Specialized Training of Military Parents)
c/o Washington PAVE
12208 Pacific Highway SW
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

ADOPTION

AASK (Adopt a Special Kid)
657 Mission St, Ste 303
San Francisco, CA 94105
(415) 543-2275
(510) 451-2023 (FAX)

Adoptive Families of America
3333 Highway 100 N
Minneapolis, MN 55422
(612) 535-4829
(612) 535-7808 (FAX)

Children's Adoption Support Services
3824 Legation St NW
Washington, DC 20015
(202) 362-3264

National Adoption Center
1500 Walnut St, Ste 701
Philadelphia, PA 19102
(800) 862-3678
(215) 735-9988
(215) 735-9410 (FAX)

National Resource Center for Special Needs Adoption
16250 Northland Dr, Ste 120
Southfield, MI 48075
(313) 443-7080
(313) 443-7099 (FAX)

National Adoption Information Clearinghouse
11426 Rockville Pike, Ste 410
Rockville , MD 20852
(301) 231-6512
(301) 984-8527 (FAX)

ARCHITECTURAL ACCESSIBILITY

Center for Accessible Housing
North Carolina State University
School of Design
Box 8613
Raleigh, NC 27695-8613
(919) 515-3082 (Voice/TDD)
(919) 515-3023 (FAX)

BIRTH DEFECTS

Association of Birth Defect Children
5400 Diplomat Cir, Ste 270
Orlando, FL 32810
(407) 629-1466 (Voice/FAX)

National Information & Advocacy Resources

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave
White Plains, NY 10605
(914) 428-7100
(914) 428-8203 (FAX)

National Birth Defects Center
30 Warren St
Boston, MA 02135
(617) 787-5958
(617) 787-9019 (FAX)

EDUCATION

AHEAD (Association on Higher Education and Disability)
PO Box 21192
Columbus, OH 43221-0192
(614) 488-4972 (Voice/TDD)
(614) 488-1174 (FAX)

National Committee for Citizens in Education
900 Second St NE, Ste 8
Washington, DC 20002
(800) 638-9675
(202) 408-0447
(202) 408-0452 (FAX)

EMPLOYMENT

JAN (Job Accommodation Network)
West Virginia University
918 Chestnut Ridge Rd, Ste 1
Morgantown, WV 26506-6080
(800) 526-7234 (Voice/TDD)
(800) 526-2262 (in Canada, Voice/TDD)

JOB (Job Opportunities for the Blind)
National Center for the Blind
1800 Johnson St
Baltimore, MD 21230
(800) 638-7518
(410) 659-9314
(410) 685-5653 (FAX)

Mainstream
3 Bethesda Metro Ctr, Ste 830
Bethesda, MD 20814
(301) 654-2400 (Voice/TDD)

National Industries for the Severely Handicapped
2235 Cedar Lane
Vienna, VA 22182
(703) 560-6800
(703) 849-8916 (FAX)

Partnership for Training and Employment Careers
1620 I St NW, LL 30
Washington, DC 20006
(202) 887-6120
(202) 887-8216 (FAX)

GENETICS

Hereditary Disease Foundation
1427 7th St, Ste 2
Santa Monica, CA 90401
(310) 458-4183
(310) 458-3937 (FAX)

National Foundation for Jewish Genetic Diseases
250 Park Ave, Ste 1000
New York, NY 10017
(212) 371-1030

HEALTH CARE

Association for the Care of Children's Health—Parents Network
7910 Woodmont Ave, Ste 300
Bethesda, MD 20814
(301) 654-6549
(301) 986-4553 (FAX)

Children's Hospice International
700 Princess St
Alexandria, VA 22314
(800) 242-4453
(703) 684-0330
(703) 684-0226 (FAX)

Parent Care
9041 Colgate St
Indianapolis, IN 46268
(317) 872-9913 (Voice/FAX)

Families of Children Under Stress (FOCUS)
PO Box 1058
Conyers, GA 30207
(404) 483-9845

INDEPENDENT LIVING

Independent Living Research Utilization Program
2323 S Shepherd, Ste 1000
Houston, TX 77019
(713) 520-0232
(713) 520-5136 (TDD)
(713) 520-5785 (FAX)

LEGAL ASSISTANCE

American Bar Association Center on Children and the Law
1800 M St NW, Ste 200 S
Washington, DC 20036
(202) 331-2250

DREDF (Disability Rights Education and Defense Fund)
2212 Sixth St
Berkeley, CA 94710
(510) 644-2555 (Voice/TDD)
(510) 841-8645 (FAX)

National Center for Law and the Deaf
Gallaudet University
800 Florida Ave NE
Washington , DC 20002
(202) 651-5373 (Voice/TDD)
(202) 651-5381 (FAX)

Pike Institute
Boston University School of Law
765 Commonwealth Ave
Boston, MA 02215-1620
(617) 353-2904
(617) 353-2906 (FAX)

The Bazelow Center for Mental Health Law
1101 15th St NW, Ste 1212
Washington, DC 20005
(202) 467-5730
(202) 467-4232 (TDD)
(202) 223-0409 (FAX)

MOTOR/MOVEMENT DISORDERS

Pathways Awareness Foundation
123 N Wacker Dr
Chicago, IL 60606
(800) 955-2445
(708) 729-1116 (FAX)

Worldwide Education and Awareness for Movement Disorders
The Neurological Institute, Box 33
710 W 168th St
New York, NY 10032
(800) 437-6682
(212) 305-5779
(212) 305-1393 (FAX)

RARE DISORDERS

Lethbridge Society for Rare Disorders
#100B, 515-7 St S
Lethbridge, AB
Canada T1J 2G8
(403) 329-0665
(403) 329-0089 (FAX)

National Organization for Rare Disorders (NORD)
100 Rt 37, PO Box 8923
New Fairfield, CT 06812-1783
(800) 999-6673
(203) 746-6518
(203) 746-6481 (FAX)

RECREATION

Boy Scouts of America Scouting for the Handicapped Service
1325 Walnut Hill Lane
Irving, TX 75038
(214) 580-2000
(214) 580-2502 (FAX)

Girl Scouts of the U.S.A. Services for Girls with Disabilities
830 Third Ave
New York, NY 10022
(212) 940-7500

Special Olympics
1350 New York Ave NW, Ste 500
Washington, DC 20005
(202) 628-3630
(202) 737-1937 (FAX)

Very Special Arts
1331 F St NW, Ste 800
Washington, DC 20004
(202) 628-2800
(202) 737-0645 (TDD)

REHABILITATION

Canadian Rehabilitation Council for the Disabled
45 Sheppard Ave E, Ste 801
Willowdale, ON
Canada M2N 5W9
(416) 250-7490
(416) 229-1371 (FAX)

Kinsman Rehabilitation Foundation of British Columbia
2256 W 12th Ave
Vancouver, BC
Canada V6K 2N5
(604) 736-8841
(604) 738-0603 (TDD)

National Rehabilitation Information Center
8455 Colesville Rd
Silver Spring, MD 20910
(800) 227-0216
(800) 346-2742 (TDD)
(301) 587-1967 (FAX)

World Rehabilitation Fund
386 Park Ave S, Ste 500
New York, NY 10016-4901
(212) 725-7875
(212) 725-8402 (FAX)

RELIGION

Christian Council on Persons with Disabilities
36272 CR 79
Warsaw, OH 43844
(614) 327-2311
(614) 327-6371 (FAX)

Keshet—Jewish Parents of Children with Special Needs
3525 W Peterson, Ste T-17
Chicago , IL 60659
(312) 588-0551
(312) 588-5825

National Catholic Office for Persons with Disabilities
PO Box 29113
Washington, DC 20017
(202) 529-2933 (Voice/TDD)
(202) 529-4678 (FAX)

RESPITE CARE

ARCH National Resource Center
800 Eastowne Dr, Ste 105
Chapel Hill, NC 27514
(800) 473-1727
(919) 490-5577
(919) 490-4905 (FAX)

SELF-HELP

American Self-Help Clearinghouse
St. Clares-Riverside Medical Ctr
25 Pocono Rd
Denville, NJ 07834
(201) 625-7101
(201) 625-9053 (TDD)
(201) 625-8848 (FAX)

National Self-Help Clearinghouse
CUNY Grad School, University Ctr
25 W 43rd St, Rm 620
New York, NY 10036
(212) 642-2944

SEXUALITY

Coalition on Sexuality and Disability
122 E 23rd St
New York, NY 10010
(212) 242-3900

SIECUS (Sex Information and Education Council Of U.S.)
130 W 42nd St, Ste 2500
New York, NY 10036-7901
(212) 819-9770.
(212) 819-9776 (FAX)

SIBLING SUPPORT

Siblings for Significant Change
United Charities Bldg
105 E 22nd St, Rm 710
New York, NY 10010
(212) 420-0776
(212) 420-0433 (FAX)

Siblings Information Network
The A.J. Pappanikou Center on Special Education and Rehab
1776 Ellington Rd
South Windsor, CT 06074
(203) 648-1205
(203) 644-2031 (FAX)

TRAVEL

Mobility International
PO Box 10767
Eugene, OR 97440
(503) 343-1284 (Voice/TDD)
(503) 343-6812 (FAX)

Travel Information Service
Moss Rehab Hospital
1200 W Tabor Rd
Philadelphia, PA 19141
(215) 456-9600
(215) 456-9602 (TDD)

Editorial Advisory Board

- **LARRY BELFORD**, Director, Marketing Research & Strategic Analysis, Ciba-Geigy Pharmaceuticals, Summit, NJ
- **LISA BLUMBERG**, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
- **T. BERRY BRAZELTON**, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
- **FRANCES P. CONNOR**, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
- **ALLEN C. CROCKER**, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
- **ELI FACTOR**, D.M.D., President, Wheelchair Motorcycle Association, Brockton, MA
- **MURRAY FEINGOLD**, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
- **SANDRA B. FLEISHMAN**, Parent and Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
- **BRUCE M. GANS**, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
- **SOL GORDON**, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
- **HERBERT J. GROSSMAN**, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
- **GOODWIN D. KATZEN**, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
- **SUSAN M. KLEIN**, Ph.D., Professor of Special Education, Department of Education, Indiana University, Bloomington, IN
- **EDWIN W. MARTIN**, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
- **JAMES MAY**, M.A., M.Ed., Project Director of the National Fathers' Network, Bellevue, WA
- **JEAN B. McGREW**, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
- **EDWARD NEWMAN**, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
- **BETTY PENDLER**, M.S., Member, New York State Developmental Disabilities Planning Council, New York, NY
- **HARVEY PRESSMAN**, President, Corporation for Opportunity Expansion, Newton, MA
- **SIEGFRIED M. PUESCHEL**, M.D., Ph.D., M.P.H., Dir., Child Dev. Ctr., Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
- **JEROME ROSNER**, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
- **HARILYN ROUSSO**, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
- **BARBARA J. SEABURY**, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
- **HOWARD SHANE**, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
- **CAROL TINGEY**, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
- **HAROLD TURNER**, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
- **IRVING KENNETH ZOLA**, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

Circle #71

Chairman of the Board.

That's my son Jedidiah. He's the reason I started Special Designs Inc.

You see, as a parent of a disabled child, I had a lot of trouble finding furniture to fit my son's special needs. Furniture that's durable and sturdy, easy to adjust and easy to take along to a restaurant or to Grandma's. Furniture that looks like it belongs in a home--not in a hospital.

Finally, I got tired of looking and made it myself. Then it occurred to me--maybe other parents have the same needs. That's how it all began. If you want to know more about our full line of furniture for disabled children, call us at the number below, or write for a free catalog.

What's it like working for Jed? Easy. I've never had a more lovable boss.

-Peter Quense

SPECIAL DESIGNS, inc
CUSTOM EQUIPMENT FOR SPECIAL KIDS

(908) 464-8825
P.O. Box 130, Gillette, NJ 07933

Amanda could hardly contain herself as they set her chair into the wheelchair swing...it seemed like she'd been waiting for this for a hundred years. She gripped the swing tightly between her fingers, took a deep breath and said, "I'm ready!" Then, as they put the swing into motion, her hesitant smile became an ear-to-ear grin. For the very first time in her eight-year-old life, Amanda was swinging.

For Amanda and others like her, our special seven-week summer program is a place where children with multiple disabilities, ages 5-21, can discover the joys of achievement.

The opportunity to make new friends...learn new skills...and increase independence awaits! We combine functional academics in special education classrooms, lifeskills in home-like environments, individualized therapies, exciting leisure/recreation activities in community-based settings and caring, professional staff members for a summer full of smiles.

Enroll Now For Summer '94!

Summer Session: June 20 - August 5
Application Deadline: April 1, 1994

HEARTSPRING™

A LIFESKILLS LEARNING CENTER

2400 JARDINE DRIVE
WICHITA · KANSAS 67219-4699
800 · 835 · 1043

Circle #38

Don't You Have Enough To Worry About...

Without Worrying About Incontinent Supplies?

DMP®

DURALINE® MEDICAL PRODUCTS

- For all of your bladder and bowel control needs - diapers, briefs, liners, underpads, catheters and more.
- Fast direct-to-your-door delivery.

Call Today For A FREE Catalog!

Circle #20

1-800-654-3376

DURALINE MEDICAL PRODUCTS
324 Warner St. • P.O. Box 67 • Leipsic, OH 45856

You Asked DynaVox To Do Even More...

"I want to tell a story."

"I want to spell and talk faster."

"I want to communicate faster with my associates."

Introducing DynaWrite.

DynaVox Was Just The Beginning.

When we first introduced the revolutionary new DynaVox™ augmentative communication aid, the response was overwhelming.

Because people found that DynaVox's modern, user-friendly technology was so much easier to learn than old-fashioned codes, most of them could begin using it in less than half an hour.

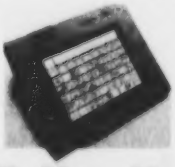
In fact, DynaVox made everyday communication so enjoyable, they wanted to go on to even greater challenges.

Introducing DynaWrite.

That's why we've created DynaWrite,™ the new software package for DynaVox that helps people compose longer, more complex messages, faster and easier than ever before.

DynaWrite uses a form of artificial intelligence called "word prediction," which *analyzes* as you write, and offers logical choices for the next word, based on the rules of grammar and a built-in 40,000-word dictionary.

Users can select from these choices with a single keystroke, so they can compose messages twice as fast as with ordinary letter-by-letter typing.



Finished compositions can then be saved, reloaded, and re-edited as needed, and spoken by the DynaVox, or output to a printer.

Dedicated To Communication.

And because the DynaVox is a totally self-contained *communication* aid, you get all this capability without having to buy a separate computer and speech synthesizer, or learn specialized computer skills.

No other single device can offer the complete spectrum of communication — from symbols, written words, and advanced word prediction, to the highest quality synthesized speech in the world. So no other device can offer the value DynaVox can.

A Straightforward Commitment.

And that's no accident. It's a direct reflection of our commitment to augmentative communication. Because we know it takes more than just technology — it takes a thorough understanding of language, continuing support, and practical, affordable solutions — to keep pace with your growing needs.

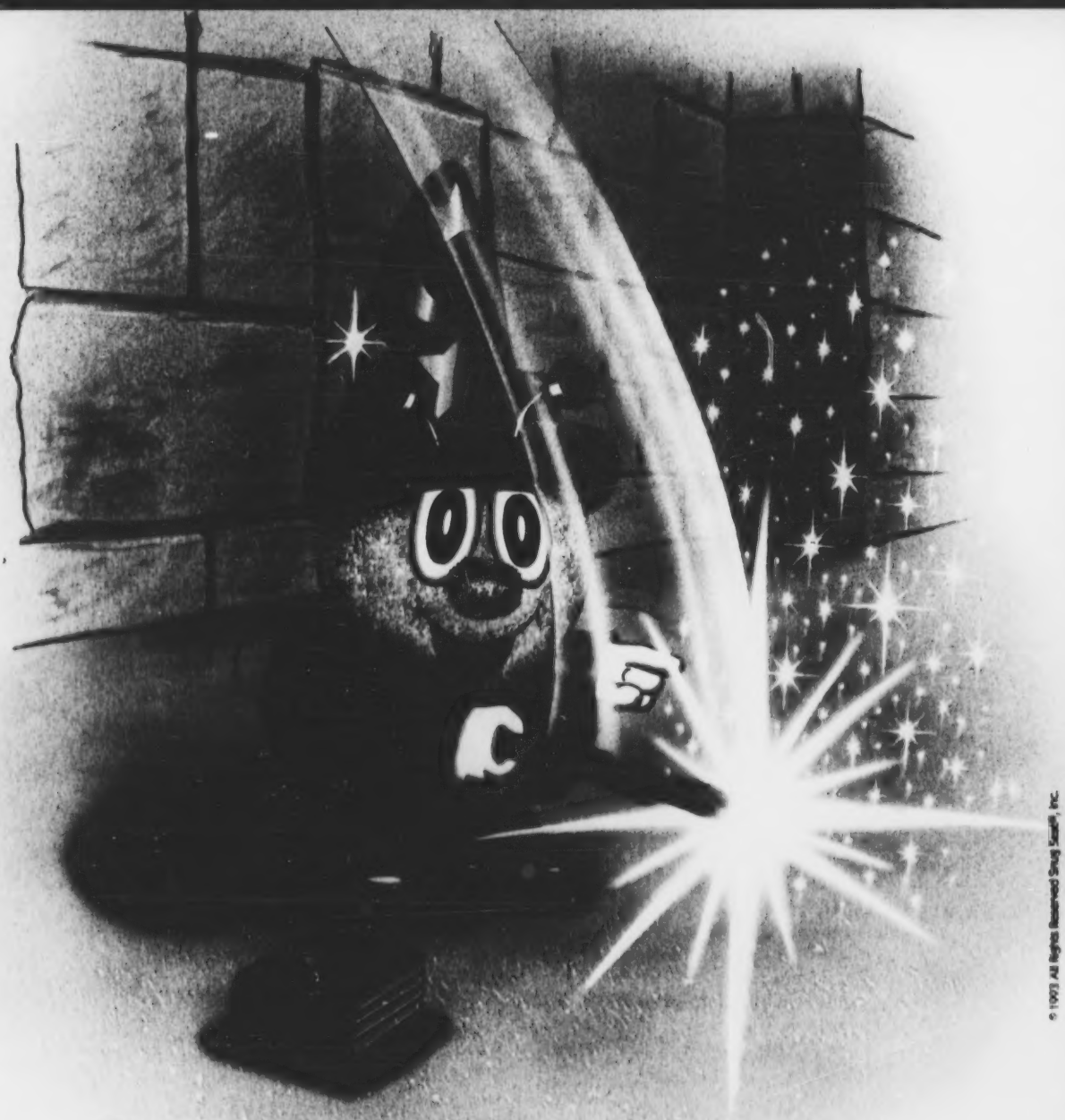
So if you know someone who might benefit from the DynaVox — and from new DynaWrite software — we urge you to contact your therapist. Or give us a call at **1-800-344-1778.**

We Hear You.

SENTIENT SYSTEMS

TECHNOLOGY INC.

Circle #68



© 1993 All Rights Reserved Snug Seat®, Inc.

This **WIZARD®** Will Amaze You!

Comfortable and fully adjustable, the WIZARD offers tilt-in-space, a fully reclining back, and elevating legrests....A magic act that no other pediatric wheelchair can perform, and it's standard with every unit!

The WIZARD easily separates into two components weighing less than 20 lbs. each....Mom can effortlessly load the WIZARD into the trunk!

The WIZARD offers these advantages

- Made of strong steel tubing, the durable WIZARD frame is guaranteed for the Lifetime of the User.
- Grows with your child from age 1 to 10 without having to purchase an expensive growth kit.
- Tackles any terrain with it's heavy duty 8"x2" front caster tires.

The Wizard
PEDIATRIC WHEELCHAIR
BY SNUG SEAT®

1-800-336-7684
Fax 1-704-847-9577
In Canada 1-800-667-3422

By SNUG SEAT®, INC. Providing Technologies For Mobility, Positioning & Transportation Since 1987

Circle #69

National Resources for Specific Disabilities and Conditions

Aarskog Syndrome

Aarskog Syndrome Parent Support Group
c/o Shannon Caranci
62 Robin Hill Ln
Levittown, PA 19055-1411
(215) 943-7131

Acidemia, Organic

Organic Acidemia Association
c/o Carol Barton
2287 Cypress Ave
San Pablo, CA 94806
(510) 724-0297

Acoustic Neuroma

See also: Neurofibromatosis

Acoustic Neuroma Association
PO Box 12402
Atlanta, GA 30355
(404) 237-8023
(404) 237-2704 (FAX)

Adrenal Hypoplasia

See also: Growth Disorders

Congenital Adrenal Hypoplasia Support Association
801 County Rd. #3
Wrenshall, MN 55797
(218) 384-3863

Agenesis of the Corpus Callosum (ACC)

ACC Network
86 N Main St
Orono, ME 04473
(207) 866-2062
(207) 581-3120 (FAX)

Aicardi Syndrome

Aicardi Syndrome Awareness and Support Group
29 Delavan Ave
Toronto, ON
Canada M5P 1T2
(416) 481-4095

Aicardi Syndrome Newsletter
5115 Troy Urbana Rd
Casstown, OH 45312
(513) 339-6033 (Voice/FAX)

AIDS

National Aids Hotline
American Society Health Assn
PO Box 13827
Research Triangle Park, NC 27709
(800) 342-2437
(800) 344-7432 (Spanish)

Albinism & Hypopigmentation

National Organization for Albinism and Hypopigmentation
1530 Locust St, Box 29
Philadelphia, PA 19102
(800) 473-2310
(215) 545-2322 (FAX)

Allergy

See: Asthma & Allergy

Alopecia Areata

National Alopecia Areata Foundation
710 C St, Ste 11
San Rafael, CA 94901
(415) 456-4644
(415) 456-4274 (FAX)

Alstrom Syndrome

See also: Diabetes Mellitus, Hearing Impairments

Alstrom Syndrome Newsletter
1006 Howard Rd
Warminster, PA 18974

Amputation

See also: Limb Disorders

American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (FAX)

National Amputation Foundation
73 Church St
Malverne, NY 11565
(516) 887-3600
(516) 887-3667 (FAX)

Anemia, Aplastic

Aplastic Anemia Foundation of America
PO Box 22689
Baltimore, MD 21203
(800) 747-2820

Anemia, Fanconi

Fanconi Anemia Research Fund/Support Group
66 Club Rd, Ste 390
Eugene, OR 97401
(503) 687-4658
(503) 687-0548 (FAX)

Angelman Syndrome

Angelman Research Group
University of Florida/Genetics
Box J-296, JHM HC
Gainesville, FL 32610-0296
(904) 392-4104
(904) 392-3051 (FAX)

Angelman Syndrome Foundation
5950-77 SW 20th Ave
Gainesville, FL 32607
(904) 332-3303
(904) 332-3303 (FAX)

Anorectal Malformations

Pull-thru Network
1 Circle Rd
Darien, CT 06820
(203) 655-6288

Aphasia

National Aphasia Association
Young People's Network
PO Box 1887
Murray Hill Station
New York, NY 10156-0611
(800) 922-4622

Arginase Deficiency

See: Urea Cycle Disorders

Argininosuccinic Aciduria

See: Urea Cycle Disorders

National Resources for Specific Disabilities and Conditions

Arnold-Chiari Syndrome
See also: Syringomyelia

Arnold-Chiari Family Network
c/o Maureen & Kevin Walsh
67 Spring St
Weymouth, MA 02188
(617) 337-2368

Arthritis

American Juvenile Arthritis Organization
1314 Spring St NW
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-0457 (FAX)

Arthrogryposis

National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
(209) 928-3688

Asthma & Allergy

Asthma and Allergy Foundation of America
1125 15th St NW, Ste 502
Washington, DC 20005
(202) 466-7643
(800) 727-8462
(202) 466-8940 (FAX)

Ataxia

National Ataxia Foundation
750 Twelve Oaks Ctr
15500 Wayzata Blvd
Wayzata, MN 55391
(612) 473-7666
(612) 473-9289 (FAX)

Attention Deficit Disorder

Children with Attention Deficit Disorders
499 NW 70th Ave, Ste 109
Plantation, FL 33317
(305) 587-3700
(305) 587-4599 (FAX)

Autism

Autism Society of America
7910 Woodmont Ave, Ste 650
Bethesda, MD 20814
(800) 328-8476
(301) 657-0881
(301) 657-0869 (FAX)

National Autism Hotline/Autism Services Center
605 Ninth St
Prichard Bldg, PO Box 507
Huntington, WV 25710-0507
(304) 525-8014
(304) 525-8026 (FAX)

Balance Disorders & Dizziness
See also: Vestibular Disorders

The EAR Foundation
2000 Church St, Box 111
Nashville, TN 37236
(800) 545-4327 (Voice/TDD)
(615) 329-7807

Pen Pal Support Group for Chronic Dizziness & Balance Disorders
Box 305
Elliot, IA 51532
(712) 767-2325

Batten's Disease

Batten's Disease Support and Research Association
2600 Parsons Ave
Columbus, OH 43207
(800) 448-4570
(614) 445-4161

Beckwith-Wiedemann Syndrome

Beckwith-Wiedemann Support Network
3206 Braeburn Cir
Ann Arbor, MI 48108
(800) 837-2976 (Parents only)
(313) 973-0263
(313) 973-9721 (FAX)

Bereavement Support

A.M.E.N.D. (Aiding Mothers & Fathers Experiencing Neonatal Death)
4324 Berrywick Terr
St Louis, MO 63128
(314) 487-7582

Center for Loss in Multiple Birth
PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123

Compassionate Friends
PO Box 3696
Oak Brook, IL 60522-3696
(708) 990-0010
(708) 990-0246 (FAX)

Brain Damage

Andrew Blake Foundation
Box 866
Winona, MN 55987
(507) 452-5734

Brain Diseases

Children's Brain Diseases Foundation
350 Parnassus Ave, Ste 900
San Francisco, CA 94117
(415) 565-6259
(415) 863-3452 (FAX)

Brain Tumors

American Brain Tumor Association
2720 River Rd, Ste 146
Des Plaines, IL 60018
(800) 886-2282 (consumer line)
(708) 827-9910
(708) 827-9918 (FAX)

Cancer

AMC Cancer Research Center
1600 Pierce St
Lakewood, CO 80214
(800) 525-3777 (Voice/TDD)

American Cancer Society
PO Box 190429
Atlanta, GA 31119-0429
(404) 816-7800
(404) 816-9443 (FAX)

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave, Ste 460
Bethesda, MD 20814
(800) 366-2223
(301) 718-2686 (FAX)

Corporate Angel Network
Westchester Cty Airport, Bldg 1
White Plains, NY 10604
(914) 328-1313
(914) 328-3938 (FAX)

G.I. Polyposis and Hereditary Colon Cancer Registry
Center for Medical Genetics
Johns Hopkins Hospital
600 N Wolfe St
Baltimore, MD 21287-4922
(410) 955-3875
(410) 955-0484 (FAX)

Intestinal Multiple Polyposis and Colorectal Cancer
c/o Ann Fagan
Reese's Crest, PO Box 11
Conyngham, PA 18219
(717) 459-1200

Carbamyl Phosphate Synthetase (CPS) Deficiency
See: Urea Cycle Disorders

Cardio-Facio-Cutaneous Syndrome

CFC Support Network
157 Alder Ave
McKee City, NJ 08232
(609) 646-5606

Cataracts

PACK: Parents of Cataract Kids
179 Hunter Ln
Devon, PA 19333
(215) 293-1917
(215) 721-9121

Celiac Sprue
See also: Gluten Intolerance

Celiac Sprue Association
PO Box 31700
Omaha, NE 68131-0700
(402) 558-0600

Central Hypoventilation Syndrome, Congenital

Congenital Central Hypoventilation Syndrome Parent Network
71 Maple St
Oneonta, NY 13820

Cerebral Palsy

United Cerebral Palsy Association
1522 K St NW, #1112
Washington, DC 20005
(800) 872-5827
(202) 842-1266 (Voice/TDD)
(202) 842-3519 (FAX)

Charcot-Marie-Tooth (CMT) Disease

Charcot-Marie-Tooth Association
Crozer Mills Enterprise Center
601 Upland Ave
Upland, PA 19015
(215) 499-7486
(215) 489-7429 (FAX)

Charcot-Marie-Tooth International
1 Springbank Dr
St Catharines, ON
Canada L2S 2K1
(905) 687-3630
(905) 687-8753

CHARGE Syndrome

CHARGE Syndrome Foundation
2004 Parkade Blvd
Columbia, MO 65202-3121
(314) 442-7604

Chromosome 9 Disorders

Support Group for 9p-
675 N Round Table Dr
Las Vegas, NV 89110
(702) 453-0788

Support Group for Monosomy 9p
43304 Kipton Nickle Plate Rd
La Grange, OH 44050
(216) 775-4255

Trisomy 9 International Parent Support
Children's Hospital of Michigan
3901 Beaubien Blvd
Detroit, MI 48201-2196
(313) 745-4513

National Resources for Specific Disabilities and Conditions

Chromosome 17p-

See: Smith-Magenis Syndrome

Chromosomes 18 & 13

Chromosome 18 Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657-4968
(210) 657-4968 (FAX)

Support Organization for Trisomy 18, 13 and Related Disorders
2982 S Union St
Rochester, NY 14624
(716) 594-4621 (Voice/FAX)

Chromosome Deletions

Chromosome Deletion Outreach
PO Box 532
Center Moriches, NY 11934
(516) 878-3510

Chromosome Inversions

National Center on Chromosome Inversions
1029 Johnson St
Des Moines, IA 50315
(515) 287-6798 (Voice/FAX)

Citrullinemia

See: Urea Cycle Disorders

Cleft Palate

Cleft Palate Foundation
1218 Grandview Ave
Pittsburgh, PA 15211
(800) 242-5338
(412) 481-1376
(412) 481-0847 (FAX)

Prescription Parents
PO Box 161
West Roxbury, MA 02132
(617) 527-0878

Cockayne Syndrome

See also: Progeria

Share and Care
1294 S St
North Valley Stream, NY 11580
(516) 825-2284

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation
PO Box 10033
Bainbridge Island, WA 98110
(206) 842-1523

Cooley's Anemia

The AHEPA Cooley's Anemia Foundation
1909 Q St, NW
Washington, DC 20009
(202) 232-6300
(202) 232-2140 (FAX)

Cooley's Anemia Foundation
105 E 22nd St, Ste 911
New York, NY 10010
(800) 221-3571
(212) 598-0911
(212) 598-4892 (FAX)

Cornelia de Lange Syndrome

Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355
(800) 753-2357
(203) 693-0159
(203) 693-6819 (FAX)

Craniofacial Disorders

AboutFace
99 Crowns Ln, 3rd Floor
Toronto, ON
Canada M5R 3P4
(800) 225-3223
(416) 944-3223
(416) 944 2488 (FAX)

AboutFace USA
PO Box 737
Warrington, PA 18976
(800) 225-3223
(215) 491-0603 (FAX)

Children's Craniofacial Association
10210 N Central Expressway
Ste 230, LB37
Dallas, TX 75231
(800) 535-3643
(214) 368-3590
(214) 368-3599 (FAX)

FACES—National Association for the Craniofacially Handicapped
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(615) 267-3124 (FAX)

Let's Face It
PO Box 711
Concord, MA 01742
(508) 371-3186

National Foundation for Facial Reconstruction
317 E 34th St, Rm 901
New York, NY 10016
(800) 422-3223
(212) 263-6656
(212) 263-7534 (FAX)

Cri Du Chat Syndrome

The 5p- Society
11609 Oakmont
Overland Park, KS 10018
(913) 469-8900

Crohn's Disease & Ulcerative Colitis

Crohn's & Colitis Foundation of America
386 Park Ave S, 17th Floor
New York, NY 10016-8804
(800) 343-3637
(212) 779-4098 (FAX)

Crouzon's Disease

See also: Craniofacial Disorders

Crouzon's/Meniere's Support Network
c/o Kathleen Handsaker
PO Box 12791
Prescott, AZ 86304-2791
(602) 445-1743

Cyclic Vomiting Syndrome

Cyclic Vomiting Syndrome Association
13180 Caroline Ct
Elm Grove, WI 53122
(414) 784-6842
(414) 821-5494 (FAX)

Cystic Fibrosis

Cystic Fibrosis Foundation
6931 Arlington Rd
Bethesda, MD 20814
(800) 344-4823
(301) 951-4422
(301) 951-6378 (FAX)

Cystinosis

See also: Kidney Disorders

Cystinosis Foundation
1212 Broadway, Ste 830
Oakland, CA 94612
(800) 392-8458

Cytochrome C Oxidase Deficiency

Cytochrome C Oxidase Deficiency Parental Research and Support Foundation
1935 Park View Pl
Aliquippa, PA 15001
(412) 375-6193

Deaf-Blind

See also: Hearing Impairments, Visual Impairments

DB-LINK: National Information Clearinghouse on Children Who are Deaf-Blind
345 N Monmouth Ave
Monmouth, OR 97361
(800) 438-9376
(800) 854-7013 (TDD)

Helen Keller National Center for Deaf-Blind Youths and Adults
111 Middle Neck Rd
Sands Point, NY 11050
(516) 944-8900
(516) 944-8637 (TDD)

Dermatomyositis

See: Polymyositis & Dermatomyositis

Diabetes Insipidus

Diabetes Insipidus and Related Disorders Network
c/o Beth Perry
Rt 2, Box 198
Creston, IA 50801
(515) 782-7838

Diabetes Mellitus

American Diabetes Association
National Service Center
1660 Duke St
Alexandria, VA 22314
(800) 232-2472
(703) 549-1500
(703) 683-2890 (FAX)

Canadian Diabetes Association
15 Toronto St, Ste 1001
Toronto, ON
Canada M5C 2E3
(416) 363-3373
(416) 363-3393 (FAX)

Juvenile Diabetes Foundation International
432 Park Ave S, 16th Floor
New York, NY 10016
(800) 533-2873
(212) 889-7575
(212) 532-8791 (FAX)

DiGeorge Syndrome

Information and Support for DiGeorge Syndrome Families
c/o Natalie Ward
27859 Lassen St
Castair, CA 91384
(805) 294-3623

National Resources for Specific Disabilities and Conditions

Down Syndrome

Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710
(516) 221-4700
(516) 221-4311 (FAX)

Canadian Down Syndrome Society
12837 76th Ave, Ste 206
Surrey, BC
Canada V3W 2V3
(604) 599-6009
(604) 599-6165 (FAX)

International Foundation for Genetic Research
400 Penn Center Blvd, Ste 721
Pittsburgh, PA 15235
(412) 823-6380
(412) 829-7304 (FAX)

National Down Syndrome Congress
1605 Chantilly Dr, Ste 250
Atlanta, GA 30324
(800) 232-6372
(404) 633-1555
(404) 633-2817 (FAX)

National Down Syndrome Society
666 Broadway, Ste 810
New York, NY 10012
(800) 221-4602
(212) 460-9330
(212) 979-2873 (FAX)

Parent Assistance Committee on Down Syndrome
208 Lafayette Ave
Peekskill, NY 10566
(914) 739-4085

Dubowitz Syndrome

Dubowitz Syndrome Parent Support Network
c/o JoAnn Wehrhan
410 N Cornwall Ave
Ventnor, NJ 08406
(609) 823-1206

Dwarfism

See also: Growth Disorders, Short Stature

Billy Barty Foundation
929 W Olive Ave, Ste C
Burbank, CA 91506
(818) 953-5410
(818) 953-7129 (FAX)

Dysautonomia

Dysautonomia Foundation
20 E 46th St, Rm 302
New York, NY 10017
(212) 949-6644
(212) 682-7625 (FAX)

Dyslexia

See also: Learning Disabilities

Dyslexia Research Institute
4745 Centerville Rd
Tallahassee, FL 32308
(904) 893-2216
(904) 893-2440 (FAX)

The Orton Dyslexia Society
Chester Bldg, Ste 382
8600 La Salle Rd
Baltimore, MD 21286-2044
(800) 222-3123
(410) 296-0232
(410) 321-5069 (FAX)

Dystonia

Dystonia Medical Research Foundation
One E Wacker Dr, Ste 2900
Chicago, IL 60601-2001
(312) 755-0198
(312) 321-5710 (FAX)

Dystrophic Epidermolysis Bullosa

Dystrophic Epidermolysis Bullosa Research Association
141 Fifth Ave, Ste 7-S
New York, NY 10010
(212) 995-2220

Ectodermal Dysplasia

National Foundation for Ectodermal Dysplasia
219 E Main, PO Box 114
Mascoutah, IL 62258-0114
(618) 566-2020
(618) 566-4718 (FAX)

Ehlers-Danlos Syndrome

Ehlers-Danlos National Foundation
P.O Box 1212
Southgate, MI 48195
(313) 282-0180
(313) 282-2793 (FAX)

Epilepsy

See also: Seizure Disorders

American Epilepsy Society
638 Prospect Ave
Hartford, CT 06105
(203) 232-4825
(203) 232-0819 (FAX)

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785-2267
(800) 332-1000
(800) 332-2070 (TDD)
(301) 459-3700
(301) 577-4941 (FAX)

Evans Syndrome

Evans Syndrome Support and Research Group
5630 Devon St
Port Orange, FL 32127
(904) 760-3031
(904) 761-6008 (FAX)

Extracorporeal Membrane Oxygenation

ECMO Moms and Dads International Parent Support
PO Box 53848
Lubbock, TX 79453
(806) 794-0259

Fanconi Anemia

See: Anemia, Fanconi

Fetal Alcohol Syndrome

FAS Adolescent Task Force
PO Box 2525
Lynnwood, WA 98036
(206) 778-4048

FAS Diagnostic Clinic
4800 Sand Point Way NE
PO Box C5371
Seattle, WA 98105
(206) 528-2660
(206) 527-3999 (FAX)

National Organization on Fetal Alcohol Syndrome
1815 H St NW, Ste 710
Washington, DC 20006
(800) 666-6327
(202) 466-6456 (FAX)

Fibrodysplasia Ossificans Progressiva (FOP)

International Fibrodysplasia Ossificans Progressiva Association
910 N Jericho Dr
Casselberry, FL 32707
(407) 365-4194 (Voice/FAX)

Fibular Hemimelia

Superkids Newsletter
60 Clyde St
Newton, MA 02160

Fragile X Syndrome

National Fragile X Foundation
1441 York St, Ste 215
Denver, CO 80206
(800) 688-8765
(303) 333-6155
(303) 333-4369 (FAX)

Freeman-Sheldon Syndrome

Freeman-Sheldon Parent Support Group
509 E Northmont Way
Salt Lake City, UT 84103
(801) 364-7060

Galactosemia

Parents of Galactosemic Children
20981 Solano Way
Boca Raton, FL 33433
(407) 852-0266

Gaucher Disease

See also: Neurometabolic Disorders

National Gaucher Foundation
19241 Montgomery Village Ave
Ste E-21
Gaithersburg, MD 20879
(800) 925-8885
(301) 990-3800
(301) 990-4898 (FAX)

Glaucoma

Foundation for Glaucoma Research
490 Post St, Ste 830
San Francisco, CA 94102
(415) 986-3162
(415) 986-3763 (FAX)

Gluten Intolerance

See also: Celiac Sprue

Gluten Intolerance Groups of North America
PO Box 23053
Seattle, WA 98102 0353
(206) 325-6980
(206) 850-2394 (FAX)

Glycogen Storage Disease

Association for Glycogen Storage Disease
PO Box 896
Durant, IA 52747
(319) 785-6038
(319) 785-6038 (FAX)

Goldenhar Syndrome

Goldenhar Syndrome Research & Information Fund
8829 Gleneagles Ln
Darien, IL 60561
(708) 910-3939 (Voice/FAX)

Hemifacial Microsomia/ Goldenhar Syndrome Family Support Network
84 Gleniffer Hill Rd
Richboro, PA 18954
(215) 364-3199

National Resources for Specific Disabilities and Conditions

Granulomatous Disease, Chronic

See also: Wegener Granulomatosis

Chronic Granulomatous Disease Association
c/o Mary Hurley
2616 Monterey Rd
San Marino, CA 91108
(818) 441-4118

Group B Strep

Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344 (Voice/FAX)

Growth Disorders

See also: Dwarfism, Short Stature

Human Growth Foundation
7777 Leesburg Pike
Falls Church, VA 22043
(800) 451-6434
(703) 883-1773
(703) 883-1776 (FAX)

Little People's Research Fund
80 Sister Pierre Dr
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0060 (FAX)

The MAGIC Foundation for Children's Growth
1327 N Harlem Ave
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808
(708) 383-0899 (FAX)

Hallerman-Streiff Syndrome

Hallerman-Streiff Support Group
1367 Beulah Park Dr
Lexington, KY 40517
(606) 273-6928

Head Injuries

National Head Injury Foundation
1776 Massachusetts Ave NW, Ste 100
Washington, DC 20036-1904
(800) 444-6443 (helpline)
(202) 296-6443
(202) 296-8850 (FAX)

Hearing Impairments

Alexander Graham Bell Association for the Deaf
3417 Volta Pl NW
Washington, DC 20007-2778
(202) 337-5220 (Voice/TDD)

American Society for Deaf Children
814 Thayer Ave
Silver Spring, MD 20910
(800) 942-2732 (Voice/TDD)

Auditory-Verbal International
2121 Eisenhower Ave
Alexandria, VA
(215) 253-6616
(215) 253-4434 (TDD)
(215) 253-6709 (FAX)

Better Hearing Institute
PO Box 1840
Washington, DC 20013
(800) 327-9355 (Voice/TDD)
(703) 750-9302 (FAX)

Canadian Hearing Society
271 Spadina Rd
Toronto, ON
Canada M5R 2V3
(416) 964-9595
(416) 964-0023 (TDD)
(416) 964-2066 (FAX)

Deaf-REACH
3521 12th St NE
Washington, DC 20017
(202) 832-6681
(202) 832-8454 (FAX)

Deafpride, Inc
1350 Potomac Ave SE
Washington, DC 20003
(202) 675-6700 (Voice/TDD)
(202) 547-0547 (FAX)

The EAR Foundation
2000 Church St, Box 111
Nashville, TN 37236
(800) 545-4327 (Voice/TDD)
(615) 329-7807

HEAR Now
9745 E Hampden Ave, Ste 300
Denver, CO 80231-4923
(800) 648-4327 (Voice/TDD)
(303) 695-7789 (FAX)

International Hearing Society
20361 Middlebelt Rd
Livonia, MI 48152
(800) 521-5247
(313) 478-2610
(313) 478-4520 (FAX)

John Tracy Clinic
806 W Adams Blvd
Los Angeles, CA 90007
(800) 522-4582 (Voice/TDD)
(213) 748-5481
(213) 747-2924 (TDD)
(213) 749-1651 (FAX)

LISTEN
PO Box 27213
Tempe, AZ 85285
(602) 921-3886 (Voice/TDD)

National Association for the Deaf
814 Thayer Ave
Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 (TDD)
(301) 587-1791 (FAX)

National Cued Speech Association
PO Box 31345
Raleigh, NC 27622
(919) 828-1218 (Voice/TDD)
(919) 828-1862 (FAX)

National Information Center on Deafness
Gallaudet University
800 Florida Ave NE
Washington, DC 20002-3695
(202) 651-5051
(202) 651-5052 (TDD)
(202) 651-5054 (FAX)

National Research Register for Hereditary Hearing Loss
Boys Town National Research Hospital
55 N 30th St
Omaha, NE 68131
(800) 835-1468 (Voice/TDD)
(402) 498-6742 (Voice/TDD)
(402) 498-6331 (FAX)

Self-Help for Hard of Hearing People
7910 Woodmont Ave, Ste 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TDD)
(301) 913-9413 (FAX)

Signing Exact English (SEE) Center for the Advancement of Deaf Children
PO Box 1181
Los Alamitos, CA 90720
(310) 430-1467 (Voice/TDD)
(310) 795-6614 (FAX)

Telecommunications for the Deaf
8719 Colesville Rd, Ste 300
Silver Spring, MD 20910
(301) 589-3786
(301) 589-3006 (TDD)
(301) 589-3797 (FAX)

TRIPOD Grapevine
2901 N Keystone St
Burbank, CA 91540
(800) 352-8888 (Voice/TDD)

VOICE for Hearing-Impaired Children
124 Eglington Ave W, Ste 420
Toronto, ON
Canada M4R 2G8
(416) 487-7719 (Voice/TDD)
(416) 487-7423 (FAX)

Heart Disorders

American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
(800) 242-8721
(214) 373-6300
(214) 706-1341 (FAX)

Congenital Heart Anomalies—Support, Education & Resources
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575

Hemophilia

Canadian Hemophilia Society
1450 City Councillors, Ste 840
Montreal, PQ
Canada H3A 2E6
(514) 848-0503
(514) 848-9661 (FAX)

National Hemophilia Foundation
110 Greene St, Rm 303
New York, NY 10012
(212) 219-8180
(212) 966-9247 (FAX)

Hemorrhagic Telangiectasis, Hereditary

HHT Foundation International
PO Box 8087
New Haven, CT 06530
(800) 448-6389
(313) 561-2537
(313) 561-4585 (FAX)

Hirschsprung Disease

See also: Intestinal Pseudo-Obstruction Syndrome

American Hirschsprung Disease Association
22½ Spruce St
Brattleboro, VT 05301
(802) 257-0603

Histiocytosis

Histiocytosis Association of America
609 New York Rd
Glassboro, NJ 08028
(800) 548-2758
(609) 881-4911
(609) 589-6614 (FAX)

Holoprosencephaly

See also: Craniofacial Disorders

Holoprosencephaly—Fighters of Defects Support Group
3032 Brereton St
Pittsburgh, PA 15219
(412) 687-6437

Hunter Syndrome

See: Mucopolysaccharidosis

Hurler Syndrome

See: Mucopolysaccharidosis

National Resources for Specific Disabilities and Conditions

Hydrocephalus

Guardians of Hydrocephalus Research Foundation
2618 Ave Z
Brooklyn, NY 11235
(718) 743-4473
(718) 743-1171 (FAX)

Hydrocephalus Association
870 Market St, Ste 955
San Francisco, CA 94102
(415) 776-4713

Hydrocephalus Support Group
PO Box 4236
Chesterfield, MO 63006-4236
(314) 532-8228

National Hydrocephalus Foundation
400 N Michigan Ave, Ste 1102
Chicago, IL 60611-4102
(815) 467-6548

Hyperoxaluria

See: Oxalosis & Hyperoxaluria

Hypopigmentation

See: Albinism & Hypopigmentation

Ichthyosis

Foundation for Ichthyosis and Related Skin Types
PO Box 20921
Raleigh, NC 27619
(800) 545-3286
(919) 782-5728
(919) 781-0679 (FAX)

Illness, Chronic

Parents of Chronically Ill Children
1527 Maryland St
Springfield, IL 62702
(217) 522-6810

Illness, Terminal

Children's Hospice International
700 Princess St, LL
Alexandria, VA 22314
(800) 242-4453
(703) 684-0330
(703) 684-0226 (FAX)

Immune Disorders

American Autoimmune Related Diseases Association
Michigan National Bank Bldg
15475 Gratiot Ave
Detroit, MI 48205
(800) 598-4668
(313) 371-8600

Incontinence

Help for Incontinent People
PO Box 544
Union, SC 29379
(800) 252-3337
(803) 579-7900
(803) 579-7902 (FAX)

Simon Foundation for Incontinence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(708) 864-9758 (FAX)

Intestinal Pseudo-Obstruction Syndrome

See also: Hirschsprung Disease

American Pseudo-Obstruction and Hirschsprung Disease Society
PO Box 772
Medford, MA 02155
(617) 395-4255
(617) 396-6868 (FAX)

Intraventricular Hemorrhage

I.V.H. Parents
PO Box 56-1111
Miami, FL 33256-1111
(305) 232-0381
Compuserve: 72167,6333
(305) 232-9890 (FAX)

Joubert Syndrome

Joubert Syndrome Parents-In-Touch Network
12348 Summer Meadow Rd
Rock, MI 49880
(906) 359-4707

Kidney Disorders

American Association of Kidney Patients
111 S Parker St, Ste 405
Tampa, FL 33606
(800) 749-2257
(813) 251-0725
(813) 254-3270 (FAX)

American Kidney Fund
6110 Executive Blvd, Ste 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0898 (FAX)

National Kidney Foundation
30 E 33rd St, 11th Fl
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 689-9261 (FAX)

Polycystic Kidney Research Foundation
922 Walnut St, Ste 411
Kansas City, MO 64106
(800) 753-2873
(816) 421-1869
(816) 421-7208 (FAX)

Klinefelter Syndrome

Klinefelter Syndrome and Associates
PO Box 119
Roseville, CA 95661-0119

Klinefelter's Syndrome Association of America
PO Box 93
Pine River, WI 54965

Klippel-Trenaunay Syndrome

Klippel-Trenaunay Support Group
c/o Judy Vessey
4610 Wooddale Ave
Edina, MN 55424
(612) 925-2596
(612) 333-8685 (FAX)

Lactic-Acidosis

Lactic-Acidosis Support Group
PO Box 480282
Denver, CO 80248-0282
(303) 287-4953

Landau-Kleffner Syndrome

See also: Aphasia, Epilepsy

CANDLE Support Group
4414 McCampbell Dr
Montgomery, AL 36106
(205) 271-3947 (Voice/FAX)

Laurence-Moon-Bardet-Biedl Syndrome

See also: Retinitis Pigmentosa

Laurence-Moon-Bardet-Biedl Syndrome Network
18 Strawberry Hill
Windsor, CT 06095
(203) 688-7880

Learning Disabilities

See also: Dyslexia

Learning Disabilities Association of America
4156 Library Rd
Pittsburgh, PA 15234
(412) 341-1515
(412) 344-0224 (FAX)

Learning Disabilities Association of Canada
323 Chapel St, Ste 200
Ottawa, ON
Canada K1N 7Z2
(613) 238-5721
(613) 235-5391 (FAX)

National Center for Learning Disabilities
381 Park Ave S, Ste 1420
New York, NY 10016
(212) 545-7510
(212) 545-9665 (FAX)

Leigh's Disease

See also: Neurometabolic Disorders

National Leigh's Disease Foundation
613 Childs St, PO Box 2222
Corinth, MS 38834
(601) 287-8069
(601) 286-2551 (FAX)

Leprosy

American Leprosy Missions
1 ALM Way
Greenville, SC 29601
(800) 543-3131
(803) 271-7040
(803) 271-7062 (FAX)

Leukemia

Leukemia Society of America
600 Third Ave, 4th Fl
New York, NY 10016
(212) 573-8484
(212) 856-9686 (FAX)

Leukodystrophy

See also: Neurometabolic Disorders

United Leukodystrophy Foundation
2304 Highland Dr
Sycamore, IL 60178
(800) 728-5483
(815) 895-3211
(815) 895-2432 (FAX)

Limb Disorders

See also: Amputation

Cherub Association of Families and Friends of Children with Limb Disorders
936 Delaware Ave
Buffalo, NY 14209
(716) 762-9997

Lissencephaly

Lissencephaly Network
716 Autumn Ridge Ln
Fort Wayne, IN 46804
(219) 432-4310

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers Voices,
Role Models,
Point of View,
and
Corporations Who Care.

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*. **BEST BUY!**

**US Fund only. Canada add an additional $6. Other Foreign countries add an additional $9.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 34

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazin

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*. **BEST BUY!**

**US Fund only. Canada add an additional $6. Other Foreign countries add an additional $9.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 3

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers Voices,
Role Models,
Point of View,
and
Corporations Who Care.

See reverse side for subscription details

National Resources for Specific Disabilities and Conditions

Liver Disorders

American Liver Foundation
1425 Pompton Ave
Cedar Grove, NJ 07009
(800) 223-0179
(201) 256-2550
(201) 256-3214 (FAX)

Lowe Syndrome

Lowe Syndrome Association
222 Lincoln St
West Lafayette, IN 47906
(317) 743-3634

Lung Diseases

American Lung Association
1740 Broadway
New York, NY 10019
(800) 586-4872
(212) 315-8700
(212) 265-5642 (FAX)

Lupus Erythematosis

The American Lupus Society
3914 Del Amo Blvd, Ste 922
Torrance, CA 90503
(800) 331-1802 (info line)
(310) 542-8891

Lupus Foundation of America
4 Research Pl, Ste 180
Rockville, MD 20850-3226
(800) 558-0121
(800) 558-0231 (Spanish)
(301) 670-9292
(301) 670-9486 (FAX)

SLE Foundation
149 Madison Ave, Ste 608
New York, NY 10016
(212) 685-4118
(212) 545-1843 (FAX)

Lyme Disease

Lyme Disease Foundation
1 Financial Plaza
Gold Bldg, 18th Floor
Hartford, CT 06103-2610
(800) 886-5953 (info line)
(203) 525-2000
(203) 525-8425 (FAX)

Macular Diseases

See also: Stargardt Disease, Visual Impairments

Association for Macular Diseases
210 E 64th St
New York, NY 10021
(212) 605-3719
(212) 605-3795 (FAX)

Malignant Hyperthermia

Malignant Hyperthermia Association of United States
PO Box 191
Westport, CT 06881-0191
(203) 847-0407
(203) 840-1772 (FAX)

Maple Syrup Urine Disease

See also: Neurometabolic Disorders

Families with Maple Syrup Urine Disease
Rt 2, Box 24-A
Flemingsburg, KY 41041
(606) 849-4679

Marfan Syndrome

National Marfan Foundation
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8712 (FAX)

Maroteaux–Lamy Syndrome

See: Mucopolysaccharidosis

McCune-Albright Syndrome

See also: Growth Disorders

McCune-Albright Syndrome Division of the MAGIC Foundation
3167 Greensburg Rd
N Canton, OH 44720
(216) 896-4455

Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)

Support Group for Medium-Chain Acyl-CoA Dehydrogenase Deficiency
805 Montrose Dr
Greensboro, NC 27410
(910) 547-0196

Mental Illness

Federation of Families for Children's Mental Health
1021 Prince St
Alexandria, VA 22314-2971
(703) 684-7710
(703) 684-5968 (FAX)

National Mental Health Association
1021 Prince St
Alexandria, VA 22314-2971
(800) 969-6642
(703) 684-7722
(703) 684-5968 (FAX)

Mental Retardation

Canadian Association for Community Living
4700 Keele St
Kinsman Bldg
North York, ON
Canada M3J 1P3
(416) 661-9611
(416) 661-2023 (TDD)
(416) 661-5701 (FAX)

The ARC
500 E Border St, Ste 300
PO Box 1047
Arlington, TX 76010
(800) 433-5255
(817) 261-6003
(817) 277-0553 (TDD)
(817) 277-3491 (FAX)

Mental Retardation/ Mental Illness

National Organization of the Dually Diagnosed
110 Prince St
Kingston, NY 12401
(800) 331-5362
(914) 331-4336
(914) 331-4569 (FAX)

Miller Syndrome

See: Nager and Miller Syndromes

Mitochondrial Disorders

Mitochondrial Disorders Education and Support Exchange
1935 Park View Pl
Aliquippa, PA 15001
(412) 375-6193

Moebius Syndrome

Moebius Syndrome Support Group
39521 Rowen Ct
Palmdale, CA 93551
(805) 267-2570

Morquio Syndrome

See: Mucopolysaccharidosis

Moyamoya Disease

See also: Vascular Malformations

Families with Moyamoya Network
c/o Dawn Gruettner
4900 McGowan St SE
Cedar Rapids, IA 52403
(319) 362-8315

Mucolipidosis Type IV

ML 4 Foundation
6 Concord Dr
Monsey, NY 10952
(914) 425-0639
(914) 425-4205

Mucopolysaccharidosis

See also: Neurometabolic Disorders

National Mucopolysaccharidosis Society
17 Kraemer St
Hicksville, NY 11801
(516) 931-6338
(516) 822-2041 (FAX)

Multiple Sclerosis

National Multiple Sclerosis Society
733 3rd Ave, 6th Fl
New York, NY 10017
(800) 532-7667
(212) 986-3240

Muscular Dystrophy

Facio-Scapulo-Humeral Society
3 Westwood Rd
Lexington, MA 02173
(617) 860-0501

Muscular Dystrophy Association
3300 E Sunrise Dr
Tuscon, AZ 85718-3208
(602) 529-2000
(602) 529-5300 (FAX)

Myelin Disorders

Myelin Messenger Newsletter
c/o Ruth Anderson
HC-29, Box 686
Stable Ln
Prescott, AZ 86301-7435
(602) 776-7556

The Myelin Project
1747 Pennsylvania Ave NW, Ste 950
Washington, DC 20006
(800) 869-3546
(202) 452-8994
(202) 785-9578

Myeloproliferative Disease

MPD Research Center
2220 Tiemann Ave
Baychester, NY 10469
(800) 435-7673
(718) 231-0230
(718) 881-1905 (FAX)

Myoclonus

Myoclonus Families United
1564 E 34th St
Brooklyn, NY 11234
(718) 252-2133

Myositis Ossificans

See: Fibrodysplasis Ossificans Progressiva (FOP)

National Resources for Specific Disabilities and Conditions

N–Acetyl Glutamate Synthetase (NAGS) Deficiency

See: Urea Cycle Disorders

Nager and Miller Syndromes

See also: Craniofacial Disorders

Nager and Miller Syndromes Support
333 Country Ln
Glenview, IL 60025
(708) 729-0701
(708) 724-6449 (Voice/FAX)
(219) 289-5611 (In Indiana)

Neonatal Illness/Prematurity

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913 (Voice/FAX)

Neurofibromatosis

See also: Acoustic Neuroma

National Neurofibromatosis Foundation
141 Fifth Ave, Ste 7-S
New York, NY 10010-7105
(800) 323-7938 (Voice/TDD)
(212) 460-8980
(212) 529-6094 (FAX)

Neurofibromatosis, Inc.
8855 Annapolis, Ste 110
Lanham, MD 20706-2924
(800) 942-6825
(410) 461-5213 (TDD)
(301) 577-0016 (FAX)

The Neurofibromatosis Institute
5415 Briggs Ave
La Crescenta, CA 91214
(818) 957-3508

Neurometabolic Disorders

Association of Neurometabolic Disorders
5223 Brookfield Ln
Sylvania, OH 43560-1809
(419) 885-1497

Niemann-Pick Disease

See also: Neurometabolic Disorders

National Niemann-Pick Disease Foundation
22201 Riverpoint Trail
Carrollton, VA 23314
(804) 357-6774

Noonan Syndrome

Noonan Syndrome Support Group
c/o Susan Espinoza
1278 Pine Ave
San Jose, CA 95125
(408) 723-5188

Ollier's Disease

Ollier's Disease Self Help Group
PO Box 52616
Shaw AFB, SC 29152-1521

Ornithine Transcarbamylase (OTC) Deficiency

See: Urea Cycle Disorders

Osteogenesis Imperfecta

Osteogenesis Imperfecta Foundation
5005 W Laurel St, Ste 210
Tampa, FL 33607
(813) 282-1161
(813) 287-8214 (FAX)

Ostomy

United Ostomy Association
36 Executive Pk, Ste 120
Irvine, CA 92714-6744
(800) 826-0826
(714) 660-8624
(714) 660-9262 (FAX)

Oxalosis & Hyperoxaluria

Oxalosis & Hyperoxaluria Foundation
PO Box 1632
Kent, WA 98035
(800) 484-9698 (ext 5100)
(206) 631-0386

Pachygyria

See: Lissencephaly

Pallister-Killian Syndrome

Pallister-Killian Family Support Group
4255 Fifth Ave SW
Naples, FL 33999
(813) 455-0400

Peutz-Jeghers Syndrome

See: Polyposis

Phenylketonuria (PKU)

Children's PKU Network
10515 Vista Sorrento Pkwy
San Diego, CA 92121
(619) 587-9421
(619) 450-5034 (FAX)

National Phenylketonuria Foundation
6301 Tejas Dr
Pasadena, TX 77503
(713) 487-4802

National PKU News
c/o Virginia Schuett
6869 Woodlawn Ave NE, Ste 116
Seattle, WA 98115
(206) 525-8140 (Voice/FAX)

Pigment Disorders

See: Albinism & Hypopigmentation, Vitiligo

Polumyositis & Dermatomyositis

National Support Group for Polumyositis & Dermatomyositis
PO Box 890
Cooperstown, NY 13326
(607) 547-5446

Polyposis

Familial Polyposis Registry
Mount Sinai Hospital
600 University Ave, Ste 1157
Toronto, Ontario
Canada M5G 1X5
(416) 586-8334
(416) 586-8644 (FAX)

Porphyria

American Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617

Prader-Willi Syndrome

Prader-Willi Syndrome Association
2510 S Brentwood Blvd, Ste 220
St Louis, MO 63144
(800) 926-4797

Progeria

International Progeria Registry
c/o W Ted Brown, M.D., Ph.D.
NY State Inst. for Basic Research in Developmental Disabilities
1050 Forest Hill Rd
Staten Island, NY 10314
(718) 494-5363
(718) 494-1026 (FAX)

Proteus Syndrome

Proteus Syndrome Association
805 E 121st Terr
Kansas City, MO 64146

Pseudoxanthoma Elasticum (PXE)

National Association for Pseudoxanthoma Elasticum
1884 Cherry St
Denver, CO 80220-1146
(303) 321-6347

Psoriasis

National Psoriasis Foundation
6600 SW 92nd, Ste 300
Portland, OR 97223
(503) 244-7404
(503) 245-0626 (FAX)

Purine Metabolic Disorders

Purine 24
5424 Beech Ave
Bethesda, MD 20814
(301) 530-0354

Reflex Sympathetic Dystrophy Syndrome

Reflex Sympathetic Dystrophy Association
116 Haddon Ave, Ste D
Haddonfield, NJ 08033
(609) 795-8845
(609) 795-8845 (FAX)

Retinitis Pigmentosa

See also: Visual Impairments

Retinitis Pigmentosa International Society for Degenerative Eye Diseases
PO Box 900
Woodland Hills, CA 91365
(800) 344-4877
(818) 992-0500
(818) 992-3265 (FAX)

RP Foundation Fighting Blindness
1401 Mt Royal Ave, 4th Floor
Baltimore, MD 21217
(800) 683-5555
(410) 225-9400
(800) 683-5551 (TDD)
(410) 225-3936 (FAX)

Retinoblastoma

See also: Visual Impairments

National Retinoblastoma Parent Group
110 Allen Rd
Bow, NH 03304
(603) 224-4085

National Resources for Specific Disabilities and Conditions

Rett Syndrome

International Rett Syndrome Association
9121 Piscataway Rd, Ste 2B
Clinton, MD 20735
(301) 856-3334
(800) 818-7388
(301) 856-3336 (FAX)

Rubella, Congenital

Rubella Project
Developmental Disabilities Ctr
St Luke's Roosevelt Hospital Ctr
428 W 59th St
New York, NY 10019
(212) 523-6280
(212) 523-7818 (TDD)
(212) 523-6241 (FAX)

RSH Syndrome

See: Smith-Lemli-Opitz Syndrome

Rubinstein-Taybi Syndrome

Rubinstein-Taybi Parent Group
c/o Lorrie Baxter
PO Box 146
Smith Center, KS 66967
(913) 697-2984

Russell-Silver Syndrome

See also: Growth Disorders, Short Stature

Association for Children with Russell-Silver Syndrome
22 Hoyt St
Madison, NJ 07940
(201) 377-4531
(201) 822-2715 (FAX)

Scheie Syndrome

See: Mucopolysaccharidosis

Scleroderma

Scleroderma Federation
Peabody Office Bldg
One Newbury St
Peabody, MA 01960
(508) 535-6600
(508) 535-6696 (FAX)

United Scleroderma Foundation
PO Box 399
Watsonville, CA 95077-0399
(800) 722-4673
(408) 728-2202
(408) 728-3328 (FAX)

Scoliosis

National Scoliosis Foundation
72 Mount Auburn St
Watertown, MA 02172
(617) 926-0397
(617) 926-0398 (FAX)

Seizure Disorders

THRESHOLD—Intractable Seizure Disorder Support Group & Newsletter
26 Stavola Rd
Middletown, NJ 07748-3728
(908) 957-0714

Short Stature

See also: Dwarfism, Growth Disorders

Little People of America
PO Box 9897
Washington, DC 20016
(800) 243-9273 (info line)

Short Stature Foundation
17200 Jamboree Rd, Ste J
Irvine, CA 92714-5828
(714) 474-4554
(800) 243-9273
(714) 261-9035 (FAX)

Sickle Cell Disease

American Sickle Cell Anemia Association
10300 Carnegie Ave
Cleveland, OH 44106
(216) 229-8600
(216) 229-4500 (FAX)

National Association for Sickle Cell Disease
3345 Wilshire Blvd, Ste 1106
Los Angeles, CA 90010
(800) 421-8453
(213) 736-5455
(213) 736-5211 (FAX)

Triad Sickle Cell Anemia Foundation
1102 E Market St
Greensboro, NC 27420-0964
(919) 274-1507
(919) 275-7984 (FAX)

Sly Syndrome

See: Mucopolysaccharidosis

Smith-Lemli-Opitz Syndrome

Smith-Lemli-Opitz (RSH) Advocacy & Exchange
222 Valley Green Dr
Aston, PA 19014
(215) 494-5287

Smith-Magenis Syndrome

Parents & Researchers Interested in Smith-Magenis Syndrome
11875 Fawn Ridge Ln
Reston, VA 22094
(703) 709-0568

Sotos Syndrome

Sotos Syndrome USA Support Association
937 Shandra Dr
Ballwin, MO 63021
(314) 256-0156

Spina Bifida

Spina Bifida Association of America
4590 MacArthur Blvd NW, #250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 (FAX)

Spina Bifida Association of Canada
220-388 Donald St
Winnipeg, MB
Canada R3B 2J4
(800) 565-9488 (Canada only)
(204) 957-1784
(204) 957-1794 (FAX)

Spinal Cord Injuries

American Paralysis Association
500 Morris Ave
Springfield, NJ 07081
(800) 225-0292
(201) 379-2690
(201) 912-9433 (FAX)

American Paralysis Spinal Cord Hotline
2201 Argonne Dr
Baltimore, MD 21218
(800) 526-3456
(410) 366-2325 (FAX)

American Spinal Injury Association
250 E Superior St, Rm 619
Chicago, IL 60611
(312) 908-3425
(312) 908-1819 (FAX)

National Spinal Cord Injury Association
600 W Cummings Pk, Ste 2000
Woburn, MA 01801
(617) 935-2722
(800) 962-9629 (hotline only)
(617) 932-8369 (FAX)

Spinal Muscular Atrophy

Families of SMA
PO Box 1465
Highland Park, IL 60035-7465
(800) 886-1762
(708) 432-5551
(708) 432-5551 (FAX)

Stargardt Disease

See also: Macular Diseases, Visual Impairments

Stargardt International and Juvenile Macular Dystrophies
PO Box 136
West Chicago, IL 60186
(708) 208-5017 (Voice/FAX)

Sturge-Weber Syndrome

Sturge-Weber Foundation
PO Box 460931
Aurora, CO 80046
(800) 627-5482
(303) 360-7290 (Voice/FAX)

Stuttering

National Center for Stuttering
200 E 33rd St
New York, NY 10016
(800) 221-2483
(212) 532-1460

National Council on Stuttering
PO Box 8791
Grand Rapids, MI 49508
(616) 241-2372

National Stuttering Project
2151 Irving St, Ste 208
San Francisco, CA 94122-1609
(800) 364-1677
(415) 566-5324
(415) 664-3721 (FAX)

Stuttering Foundation of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(202) 363-3199
(901) 452-3931 (FAX)

Stuttering Resource Foundation
123 Oxford Rd
New Rochelle, NY 10804
(800) 232-4773
(914) 632-3925
(914) 235-0615 (FAX)

Sudden Infant Death Syndrome (SIDS)

See also: Bereavement Support

National Sudden Infant Death Syndrome Alliance
10500 Little Patuxent Pkwy, #420
Columbia, MD 21044-3505
(800) 221-7437
(410) 964-8000

National Resources for Specific Disabilities and Conditions

Syringomyelia

See also: Arnold-Chiari Syndrome

American Syringomyelia Alliance Project
PO Box 1586
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (FAX)

Tay-Sachs Disease

See also: Neurometabolic Disorders

National Tay-Sachs and Allied Diseases Association
2001 Beacon St, Ste 204
Brookline, MA 02146
(617) 277-4463
(617) 277-0134 (FAX)

Thalassemia

See: Cooley's Anemia

Thrombocytopenia-Absent Radius (TAR) Syndrome

Thrombocytopenia-Absent Radius Syndrome Association
212 Sherwood Dr, RD 1
Linwood, NJ 08221-9745
(609) 927-0418

Tourette Syndrome

Tourette Syndrome Association
42-40 Bell Blvd
Bayside, NY 11361-2861
(800) 237-0717
(718) 224-2999
(718) 279-9596 (FAX)

Treacher Collins Syndrome

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(802) 649-3020

Tuberous Sclerosis

National Tuberous Sclerosis Association
8000 Corporate Dr, Ste 120
Landover, MD 20785
(800) 225-6872
(301) 459-9888
(301) 459-0394 (FAX)

Turner's Syndrome

The Turner's Syndrome Society
7777 Keele St, Fl 2
Concord, ON
Canada L4K 1Y7
(416) 660-7766
(416) 660-7450 (FAX)

Turner's Syndrome Society of the US
15500 Wayzata Blvd, #768-214
12 Oak Ctr
Wayzata, MN 55391
(612) 475-9944
(612) 475-9949 (FAX)

Urea Cycle Disorders

National Urea Cycle Disorders Foundation
4559 Vauxhall Rd
Richmond, VA 23234
(908) 851-2731

Vascular Malformations

National Vascular Malformations Foundation
8320 Nightingale
Dearborn Heights, MI 48127
(313) 274-1243

Vestibular Disorders

See also: Balance Disorders & Dizziness

Vestibular Disorders Association
PO Box 4467
Portland, OR 97208-4467
(800) 837-8428
(503) 229-7705
(503) 229-8064 (FAX)

Visual Impairments

See also: Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Stargardt Disease

American Council of the Blind
1155 15th St NW, Ste 720
Washington, DC 20005
(800) 424-8666
(202) 467-5081

American Foundation for the Blind
15 W 16th St
New York, NY 10011
(800) 232-5463
(212) 620-2000

American Printing House for the Blind
1839 Frankfort Ave, PO Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405
(502) 895-1509 (FAX)

Blind Children's Fund
8500 W Capitol Dr
Milwaukee, WI 53222
(414) 464-3000
(414) 464-5693 (FAX)

Canadian National Institute for the Blind
1929 Bayview Ave
Toronto, ON
Canada M4G 3E8
(416) 480-7415
(416) 480-7414
(416) 480-7417 (TDD)
(416) 480-7699 (FAX)

Council of Citizens with Low Vision International
5707 Brockton Dr, Ste 302
Indianapolis, IN 46220-5481
(800) 733-2258
(317) 251-6588 (FAX)

National Alliance of Blind Students
1155 15th St NW, Ste 720
Washington, DC 20005
(800) 424-8666
(202) 467-5081

National Association for Parents of the Visually Impaired
PO Box 317
Watertown, MA 02272-0317
(800) 562-6265
(617) 972-7441
(617) 972-7444

National Association for Visually Handicapped
22 W 21st St, 6th Fl
New York, NY 10010
(212) 889-3141
(202) 727-2931 (FAX)

National Federation of the Blind
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314
(410) 752-5011 (BBS)
(410) 685-5653 (FAX)

National Society to Prevent Blindness
500 E Remington Rd
Schaumburg, IL 60173-4557
(800) 331-2020
(708) 843-2020
(708) 843-8458 (FAX)

Recording for the Blind
20 Roszel Rd
Princeton, NJ 08540
(609) 452-0606

VISION Foundation
818 Mt. Auburn St
Watertown, MA 02172
(800) 852-3029 (in MA)
(617) 926-4232
(617) 926-1412 (FAX)

Vitiligo

National Vitiligo Foundation
PO Box 6337
Tyler, TX 75711
(903) 534-2925
(903) 534-8075 (FAX)

Von Hippel-Lindau Syndrome

See also: Ataxia, Balance Disorders & Dizziness

Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd
Brookline, MA 02146
(617) 232-5946 (evenings)
(617) 734-8233 (FAX)

Von Hippel-Lindau Syndrome Foundation
32 Beaverson Blvd, Bldg 2, Ste B
Brick, NJ 08723
(908) 262-9708
(908) 262-9709 (FAX)

Wegener Granulomatosis

See also: Granulomatous Disease, Chronic

Wegener Granulomatosis Support Group
PO Box 1518
Platte River City, MO 64079-1518
(800) 277-9474

Williams Syndrome

Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(313) 541-3630
(313) 541-3631 (FAX)

Wilson's Disease

Wilson's Disease Association
PO Box 75324
Washington, DC 20013
(703) 636-3003 (Voice/TDD)
(703) 636-3014

Wolf-Hirschhorn Syndrome (4p-)

4p- Parent Contact Group
c/o Becky & Tom Richardson
3200 Rivanna Ct
Woodbridge, VA 22192
(703) 491-0309

Wolf-Hirschhorn Syndrome (4p-) Support Group and Newsletter
Virginia Ct
Amherst, OH 44001
(216) 282-1460

Xeroderma Pigmentosum

Xeroderma Pigmentosum Registry
New Jersey Medical School
Dept. of Pathology, Rm C-520
Medical Science Bldg 185 S
Orange Ave
Newark, NJ 07103-2714
(201) 982-4405

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558 Circle #86

TM2000 SERIES by MARKELL

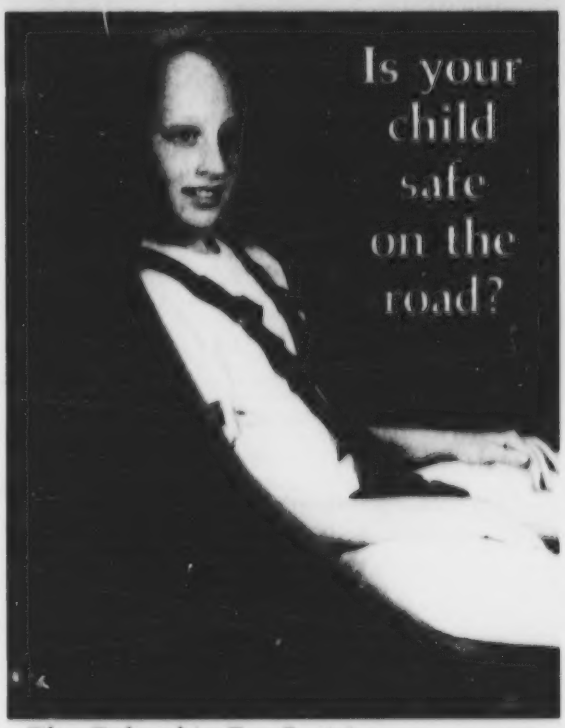
Markell is committed to the best in therapeutic foot products. With an eye to the future we have created a true orthopedic sneaker for children.

The TM200 Series has the following features:

- Symetrical straight last.
- Added depth – 3/16" (5mm) deeper than our conventional straight last shoes, to accommodate orthotics, AFO's and internal modifications.
- Extended counters firm enough to provide support and stability.
- Whole and half sizes from Infants' 6 to Youths' 2.
- Widths – a choice of Medium to Wide.
- Removable cushioned insoles.

Available through shoe stores and orthotics & prosthetics facilities worldwide.

© M.J.Markell Shoe Co., Inc.
504 Saw Mill River Rd., Yonkers, NY 10702, USA
or P.O.Box 246, Yonkers, NY 10702, USA Circle #51

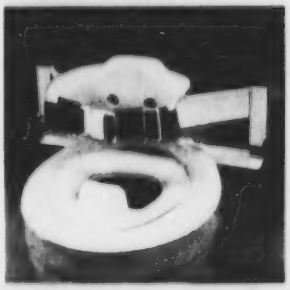


The Columbia Car Seat is your answer
Complete head and body support you can adjust as your child grows . . . in fact, the Columbia Car Seat has passed Federal crash tests for a child from **20 to 102 lbs.**, up to 5 ft. tall!

- Exceeds all Federal safety standards
- Approved for cars, busses, airplanes
- Durable good looks, washable fabric
- Versatile – use as a comfortable support seat anywhere

Ask for our FREE Full Color Catalog of convenient, helpful products

It includes a full line of Toilet Supports so you can choose the exact one to suit your child. They mount and dismount easily on any toilet anywhere.



Contact us for your nearest dealer

COLUMBIA

Vocal Assistant™

The Vocal Assistant provides hand-held basic speech at a very affordable price.

The Vocal Assistant is a digital record and playback communication device. Record 16 messages (any voice, any language) in just minutes. Each message is available for playback with the touch of a key.

A paper overlay slides into the water resistant keypad so you can use pictures or words to illustrate the message stored in each key.

Features

- 16-message keypad with overlay pocket
- Built-in microphone and speaker
- Lightweight and compact
- Automatically conserves battery power between uses
- Records messages in any order
- Remembers messages during battery replacement
- Uses a standard 9 volt alkaline or rechargeable battery

gmr labs

1030 E. El Camino Real #308
Sunnyvale, CA 94087

Phone 408 · 985 · 7200
Fax 408 · 243 · 3731

VISA

Circle #34

AccessAble
ENVIRONMENTS + PRODUCTS

BARRIER-FREE ACCESSSHOWERS FOR THE WHOLE FAMILY

- ✔ **Accesshower** kit with door to replace inaccessible bathtubs
- ✔ **Accesshower** system with door for the new accessible bathroom
- ✔ **FreeAccess** accordion-fold or **BeautyAccess** bi-fold barrier-free showerdoor kits for existing showers
- ✔ **Anywhere, Anytime Accesshower** for portable temporary use (AVAIL MID-'94)

SHOWER, BATH, TOILET SEATING

- ✔ **AdjustEase** and **ReclinEase** reclined shower/bath chairs for infants, children, teens and adults
- ✔ **RollEase** wheeled upright shower-toilet chairs in many sizes and capacities
- ✔ AccessAble chairs have the best easy-roll, no-rust wheels available and also offer many optional adaptive features

SHOWEREASE ACCESS PRODUCTS

- ✔ **SoloAccess Ramp,** portable, for 1"-3" barriers, 20"L x 30"W, 12 lbs
- ✔ **SitEase** wall-mounted benches
- ✔ **SafEase** adjustable grab bars in various sizes and shapes
- ✔ **Accessspray** adaptive hose showers specially-mounted on sturdy grab bars
- ✔ **TempEase** anti-scald shower controls

Circle #9

No risk!

CALL TO ORDER FREE INFORMATION!
1 800 285 2525

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich

ORTHOPAEDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

Circle #36

Absolutely No Rinsing Required

Less than 5 minutes for a cleansing shampoo

No-Rinse Body Bath
Less than 10 minutes for a refreshing bath

No longer is bathing an ordeal

Call, write or FAX for free samples

No-Rinse® Since 1948

900 E. Franklin St.,
Centerville, Ohio 45459
Toll free 1-800-223-9348
FAX 1-513-433-0779

Shampoo • Body Bath

The original liquid, non-rinsing hair and body cleansers

Ask your pharmacy or retailer for No-Rinse

Circle #1

Columbia makes bathtime easier!

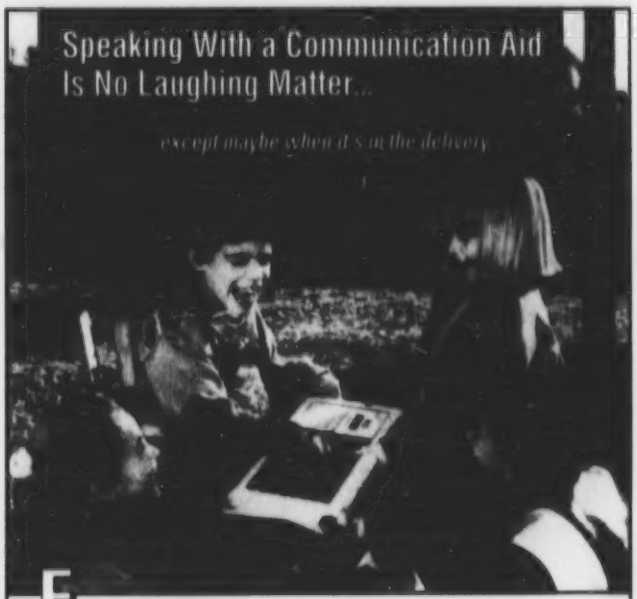
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile - use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?

- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA



For telling a joke, saying "I love you", or just expressing a need, **PALLS®** is the only device that offers three flexible programs for any level of communication.

So if you know someone who may have a few good jokes to tell, give us a call–you'd be surprised at what we can do with the delivery.

(800) 227-0735 U.S. (800) 263-8700 Canada

PhonicEar®
Innovative Communication Technologies

Circle #60

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D 30

P.O. Box 150, New Kent, Virginia 23124

Circle #18

Parent Training & Information Centers

Parent Training and Information Programs (PTIs) are funded by the Division of Personnel Preparation, Office of Special Education Programs, U.S. Department of Education. Their stated mission is "to provide training and information to parents to enable [them] to participate more effectively with professionals in meeting the educational needs of children with disabilities."

PTIs can help parents to:

- Understand their children's specific needs;
- Communicate more effectively with professionals;
- Participate in the educational planning process; and
- Obtain information about relevant programs, services and resources.

ALABAMA

Special Education Action Committee
PO Box 161274
Mobile, AL 36616-2274
(800) 222-7322 (in AL)
(205) 478-1208 (Voice/TDD)
(205) 473-7877 (FAX)

ALASKA

Alaska PARENTS Resource Ctr
540 International Airport Rd, Ste 250
Anchorage, AK 99518
(800) 478-7678 (in AK)
(907) 563-2246
(907) 790-2248 (FAX)

ARIZONA

Pilot Parent Partnerships
2150 E Highland Ave, Ste 105
Phoenix, AZ 85016
(602) 468-3001 (Voice/TDD)
(602) 468-3001 (FAX)

ARKANSAS

Arkansas Disability Coalition
10002 West Markham, Ste B7
Little Rock, AR 72205
(501) 221-1330 (Voice/TDD)
(501) 221-9067 (FAX)

FOCUS
2917 King St, Ste C
Jonesboro, AR 72401
(501) 935-2750
(501) 221-1330 (Voice/TDD)
(501) 931-1111 (FAX)

CALIFORNIA

Northern Coalition for Parent Training and Information
DREDF
2212 6th St
Berkeley, CA 94710
(510) 644-2555
(510) 841-8645 (FAX)

Northern Coalition for Parent Training and Information
Exceptional Parents Unlimited
4120 N 1st St
Fresno, CA 93726
(209) 229-2000
(209) 229-2956 (FAX)

Northern Coalition for Parent Training and Information
Matrix, A Parent Network and Resource Center
PO Box 6541
San Rafael, CA 94903
(415) 499-3877
(415) 507-9457 (FAX)

Northern Coalition for Parent Training and Information
Parents Helping Parents
535 Race St, Ste 140
San Jose, CA 95126
(408) 288-5010
(408) 288-7493 (FAX)

Parents Helping Parents
1801 Vincente St
San Francisco, CA 94116
(415) 564-0722
(415) 681-1065 (FAX)

Team of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805-6546
(714) 533-8275 (Voice/TDD)
(714) 533-2533 (FAX)

COLORADO

PEAK Parent Center
6055 Lehman Dr, Ste 101
Colorado Springs, CO 80918
(800) 284-0251
(719) 531-9400
(719) 531-9403 (TDD)
(719) 531-9452 (FAX)

CONNECTICUT

Connecticut Parent Advocacy Center
5 Church Ln
PO Box 579
East Lyme, CT 06333
(800) 445-2722 (in CT)
(203) 739-3089 (Voice/TDD)
(203) 739-7460 (FAX)

DELAWARE

Parent Information Center of Delaware
700 Barksdale Rd, Ste 6
Newark, DE 19711
(302) 366-0152
(302) 366-0178 (TDD)
(302) 366-0276 (FAX)

DISTRICT OF COLUMBIA

COPE
PO Box 90498
Washington, DC 20090-0498
(202) 526-6814
(202) 832-2180 (FAX)

FLORIDA

Family Network on Disabilities
5510 Gray St, Ste 220
Tampa, FL 33609-3510
(813) 289-1122 (Voice/TDD)
(813) 286-8614 (FAX)

GEORGIA

Parents Educating Parents
Georgia ARC
1851 Ram Runway, Ste 104
College Park, GA 30337
(404) 761-2745 (Voice/TDD)
(404) 761-3150
(404) 761-2258 (FAX)

HAWAII

AWARE/Learning Disabilities Association of Hawaii
200 N Vineyard Blvd, Ste 310
Honolulu, HI 96817
(808) 536-2280 (Voice/TDD)
(808) 537-6780 (FAX)

Parent Training & Information Centers

IDAHO

Idaho Parents Unlimited
Parent Education Resource Ctr
4696 Overland Rd, Ste 478
Boise, ID 83705
(800) 242-4785 (in ID)
(208) 342-5884 (Voice/TDD)
(208) 342-1408 (FAX)

ILLINOIS

Designs for Change
6 N Michigan Ave, Ste 1600
Chicago, IL 60602
(312) 857-9292
(312) 857-1013 (TDD)
(312) 857-9299 (FAX)

Family Resource Center on Disabilities
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(800) 952-4199 (in IL)
(312) 939-3513
(312) 939-3519 (TDD)
(312) 939-7297 (FAX)

INDIANA

Indiana Resource Center for Families with Special Needs
833 E Northside Blvd, Bldg 1, R
South Bend, IN 46617
(800) 332-4433 (in IN)
(219) 234-7101
(219) 234-7279 (FAX)

IOWA

Iowa Pilot Parents
33 N 12th St
PO Box 1151
Fort Dodge, IA 50501
(800) 952-4777
(515) 576-5870 (Voice/TDD)
(515) 576-8209 (FAX)

KANSAS

Families Together
1023 SW Gage Blvd
Topeka, KS 66604
(913) 273-6343 (Voice/TDD)
(913) 273-6385 (FAX)

KENTUCKY

Kentucky Special Parent Involvement Network
2210 Goldsmith Ln, Ste 118
Louisville, KY 40218
(502) 456-0923
(502) 456-0893 (FAX)

LOUISIANA

Project Prompt
4323 Division St, Ste 110
Metairie, LA 70002
(800) 766-7736
(504) 888-9111
(504) 888-0246 (FAX)

MAINE

Special-Needs Parent Information Network
PO Box 2067
Augusta, ME 04338-2067
(800) 870-7746
(207) 582-2504 (Voice/TDD)
(207) 582-3638 (FAX)

MARYLAND

Parents Place of Maryland
7257 Parkway Dr, Ste 210
Hanover, MD 21076
(410) 712-0900 (Voice/TDD)
(410) 712-0902 (FAX)

MASSACHUSETTS

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(800) 331-0688 (in MA)
(617) 482-2915
(617) 695-2939 (FAX)

MICHIGAN

Citizens Alliance to Uphold Special Education
313 S Washington Sq, Ste 040
Lansing, MI 48933
(800) 221-9105 (in MI)
(517) 485-4084 (Voice /TDD)
(517) 485-4145 (FAX)

Parents are Experts
23077 Greenfield Rd, Ste 205
Southfield, MI 48075
(313) 557-5070 (Voice/TDD)
(313) 557-4456 (FAX)

MINNESOTA

PACER Center
4826 Chicago Ave S
Minneapolis, MN 55417
(800) 537-2237 (parents, in MN)
(612) 827-2966 (Voice/TDD)
(612) 827-3065 (FAX)

MISSOURI

Missouri Parents Act
1722 S Glenstone, Ste 125
Springfield, MO 64131
(800) 743-7634 (in MO)
(417) 882-7434 (Voice/TDD)
(417) 882-8413 (FAX)

MPACT—Kansas City Office
1115 E 65th St
Kansas City, MO 64131
(816) 333-6833
(816) 333-5685 (TDD)
(816) 333-2267 (FAX)

MPACT—St Louis Office
8631 Delmar, Ste 300
St Louis, MO 63124
(800) 995-3160
(314) 997-7622 (Voice/TDD)
(314) 997-5518 (FAX)

MONTANA

Parents, Let's Unite for Kids
EMC/Special Education Building
1500 N 30th St
Billings, MT 59101-0298
(406) 657-2055 (Voice/TDD)
(406) 657-2061 (FAX)

NEBRASKA

Nebraska Parents Center
3610 Dodge St, Ste 102
Omaha, NE 68131
(800) 284-8520 (voice/TDD in NE)
(402) 346-0525
(402) 346-5253 (FAX)

NEVADA

Nevada Parent Connection
3380 S Arville Blvd, Ste J
Las Vegas, NV 89102
(800) 508-4464 (in NV)
(702) 252-0259, ext. 112 & 113
(702) 252-8780 (FAX)

NEW HAMPSHIRE

Parent Information Center
151A Manchester St
PO Box 1422
Concord, NH 03302-14226
(800) 232-0986 (in NH)
(603) 224-6299
(603) 224-7005 (voice/TDD)
(603) 224-4365 (FAX)

NEW JERSEY

Statewide Parent Advocacy Network
516 North Ave E
Westfield, NJ 07090
(908) 654-7726
(908) 654-7880 (FAX)

NEW MEXICO

EPICS Project
Parents Reaching Out
1127 University Blvd NE
Albuquerque, NM 87102
(800) 524-5176 (in NM)
(505) 842-9045 (Voice/TDD)
(505) 842-1451 (FAX)

EPICS Project SW
Communication Resources
PO Box 788
412 Camino Don Tomas
Bernalillo, NM 87004
(800) 765-7320
(505) 867-3396 (Voice/TDD)
(505) 867-3398 (FAX)

NEW YORK

Advocates for Children of New York
24-16 Bridge Plaza S
Long Island City, NY 11101
(718) 729-8866 (Voice/TDD)
(718) 729-8931 (FAX)

Parent Network Center
1443 Main St
Buffalo, NY 14209
(800) 724-7408 (in NY)
(716) 885-1004
(716) 885-3527 (TDD)
(716) 885-9597 (FAX)

Resources for Children with Special Needs
200 Park Ave S, Ste 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (FAX)

NORTH CAROLINA

Exceptional Children's Assistance Center
PO Box 16
Davidson, NC 28655
(800) 962-6817 (in NC)
(704) 892-1321
(704) 892-5028 (FAX, call first)

Families First Coalition
300 Enola Rd
Morganton, NC 28655
(800) 822-3477 (in NC)
(704) 433-2662
(704) 438-6457 (FAX)

NORTH DAKOTA

Pathfinder Parent Training and Information Center
1600 Second Ave SW
Minot, ND 58701
(800) 245-5840 (in ND)
(701) 852-9426
(701) 838-9324 (FAX)

OHIO

Child Advocacy Center
1821 Summit Rd, Ste 303
Cincinnati, OH 45237
(800) 821-2400 (in OH)
(513) 821-2400 (Voice, TDD)
(513) 821-2442 (FAX)

Ohio Coalition for the Education of Handicapped Children
933 High St, Ste 106B
Worthington, OH 43085
(614) 431-1307 (Voice/TDD)
(614) 382-2399 (FAX)

Parent Training & Information Centers

OKLAHOMA

Parents Reaching Out in Oklahoma Project
1917 S Harvard Ave
Oklahoma City, OK 73128
(800) 759-4142
(405) 681-9710 (Voice/TDD)
(405) 685-4006 (FAX)

OREGON

Oregon COPE Project
999 Locust St, NE
Salem, OR 97303
(503) 373-7477 (Voice/TDD)
(503) 373-7477 (FAX, call first)

PENNSYLVANIA

Mentor Parent Program
Rt 257, PO Box 718
Seneca, PA 16346
(800) 447-1431 (in PA)
(814) 676-8615
(814) 676-8615 (FAX)

Parent Education Network
333 E 7th Ave
York, PA 17404
(800) 522-5817 (Voice/TDD in PA)
(717) 845-9722 (Voice/TDD)
(717) 848-3654 (FAX)

Parents Union for Public Schools
311 S Juniper St, Ste 602
Philadelphia, PA 19107
(215) 546-1166
(215) 731-1688 (FAX)

PUERTO RICO

Asociacion de Padres Por Bienestar de Ninos Impedidos de PR
PO Box 21301
Rio Piedras, PR 00928-1301
(809) 763-4665
(809) 765-0345
(809) 765-0345 (FAX)

RHODE ISLAND

Rhode Island Parent Information Network
Independence Sq
500 Prospect St
Pawtucket, RI 02860
(800) 464-3399 (in RI)
(401) 727-4144 (Voice)
(401) 727-4151 (TDD)
(401) 725-9960 (FAX)

SOUTH CAROLINA

PRO-PARENTS
2712 Middleburg Dr, Ste 102
Columbia, SC 29204
(800) 759-4776 (in SC)
(803) 779-3859 (Voice/TDD)
(803) 252-4513 (FAX)

SOUTH DAKOTA

South Dakota Parent Connection
PO Box 84813
Sioux Falls, SD 57118-4813
(800) 640-4553 (in SD)
(605) 335-8844 (Voice/TDD)
(605) 335-8504 (FAX)

TENNESSEE

Support and Training for Exceptional Parents
1805 Hayes St, Ste 100
Nashville, TN 37203
(800) 280-7837
(800) 848-0298 (TDD)
(615) 639-0125
(615) 636-8217 (FAX)

TEXAS

Partners Resource Network
277 N 18th, Ste 2
Beaumont, TX 77707-2203
(800) 866-4726
(409) 838-2366
(409) 838-2351 (FAX)

Project PODER
2300 W Commerce, Ste 205
San Antonio, TX 78207
(800) 682-9747
(210) 222-2637
(210) 222-2638 (FAX)

Special Kids
PO Box 61628
Houston, TX 77208-1628
(713) 643-9576
(713) 643-6291 (FAX)

UTAH

Utah Parent Center
2290 E 4500 S, Ste 110
Salt Lake City, Utah 84117
(800) 468-1160 (in UT)
(801) 272-1051
(801) 272-8907 (FAX)

VERMONT

Vermont Parent Information Center
1 Mill St
Burlington, VT 05401
(800) 639-7170 (in VT)
(802) 658-5315
(802) 658-5395 (FAX)

VIRGINIA

Parent Education Advocacy Training Center
228 S Pitt St, Ste 300
Alexandria, VA 22314
(800) 869-6782 (in VA, WV, MD)
(703) 836-2953
(703) 836-3026 (TDD)
(703) 836-5869 (FAX)

WASHINGTON

PAVE/STOMP Specialized Training of Military Parents
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

Touchstones
6721 51st Ave S
Seattle, WA 98118
(206) 721-0867
(206) 721-2422 (FAX)

Washington PAVE
6316 S 12th St
Tacoma, WA 98465
(800) 572-7368
(206) 545-2266 (Voice/TDD)
(206) 566-8052 (FAX)

WEST VIRGINIA

West Virginia Parent Training & Information Center
104 East Main St
Colonial Village, Ste 3-B
Clarksburg, WV 26301
(800) 281-1436 (Voice/TDD in WV)
(304) 624-1436 (Voice/TDD)
(304) 624-1438 (FAX)

WISCONSIN

Parent Education Project of Wisconsin
2192 S 60th St
West Allis, WI 53219
(800) 231-8382 (in WI)
(414) 328-5520

WYOMING

Wyoming PIC
5 N Lobban
Buffalo, WY 82834
(800) 660-9742 (in WY)
(307) 684-2277 (Voice/TDD)
(307) 684-5314 (FAX)

5 Models Available Now

BIGFOOT

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Circle #42 Photo used by permission Bigfoot 4 X 4 Inc. St. Louis, MO

Our Toilet Supports are so adjustable toddlers thru adults can use the same one. We have High Back and Low Back versions. Pommels, urine deflectors, foot rests and smaller seats for young children are available.

Our NEW Bath/Shower Chairs are the most adjustable ones made. We have 3 models - an Elevated, a Standard, and a Roll-In Shower chair. Each model has 6 sizes to maximize the time of its use. Your child and you

For a free brochure call or write:

The Adaptive Design Shop

12847 Pt. Pleasant Drive
Fairfax, VA 22033
703-631-1585

Circle #3

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

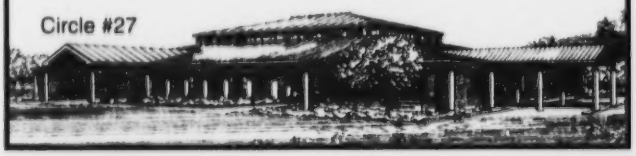
Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

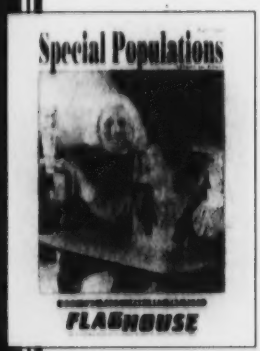
EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27



FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE



Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- Aquatic Aids/Sports Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE INC.

150 No. MacQuesten Pkwy., Suite 95083 Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

Circle #29

INTERIOR PLANNING & DESIGN, INC.

Custom designed to your needs:
Institutional, Home,
Office,
Health Care.

Turnkey operation, including furniture,
U.S.A. and International.

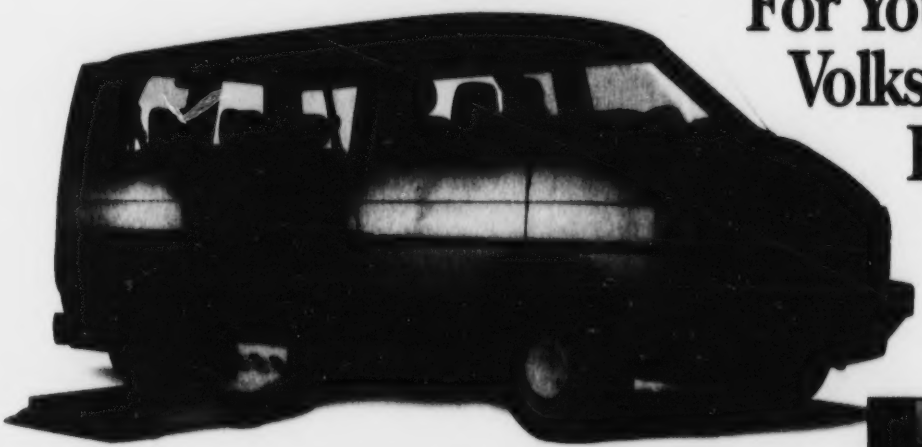
2 Annabelle Lane
Florham Park, NJ 07932
(201) 966-0220
Fax (201) 966-6894

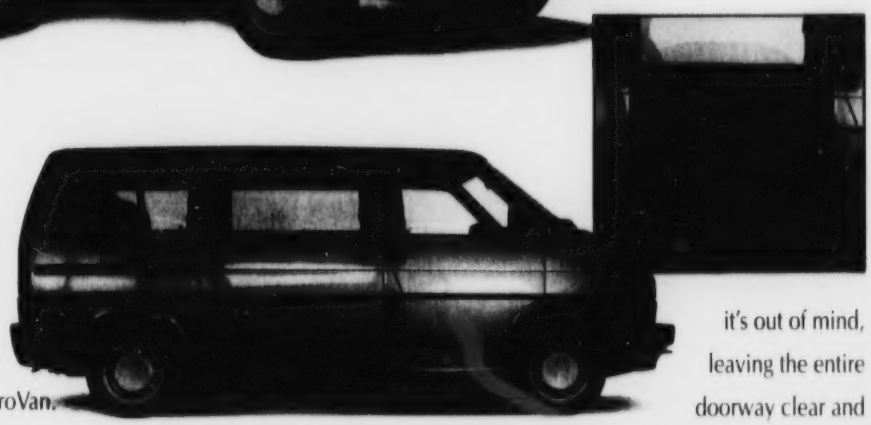
Circle #89

34

The best wheelchair lift you've never seen: MIRAGE™

For Your Volkswagen EuroVan®





The best feature on our newest wheelchair lift is invisible. When the patented Mirage lift is not in use, it stows away in a hidden protective enclosure beneath the floor of your EuroVan. it's out of mind, leaving the entire doorway clear and maximizing your floor space.

Mirage is easily available when you need it, letting you raise, lower, stow and deploy quietly with the touch of a button. Its aluminum-and-steel construction provides strength and durability. And when Mirage is out of sight,

Convenience like this is hard to find...unless you know where to look. Call Ricon at **1-800-322-2884** or your VW® dealer for more information on the Mirage lift.

Ricon Corporation
12450 Montague St.
Pacoima, CA 91331

Tel. (818) 899-7588
1-800-322-2884
Fax (818) 890-3354

Ricon Canada Inc.
14750 Gouin Blvd. W.
Pierrefonds, Quebec
Canada H9H 1B2

Tel. (514) 626-0261
Fax (514) 626-0264

RICON
Innovation in Mobility

Ricon U.K. Ltd.
153 Bennett St.
Ardwick, Manchester
United Kingdom
M12 5BW

Tel. 061-274-3711
Fax 061-274-3706

Ricon Scandinavia AS
Stanseveien 27
N-0976 Oslo
Norway

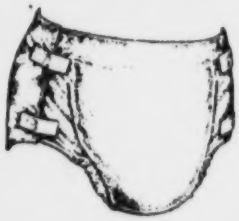
Tel. 22 16 70 90
Fax 22 16 60 90

Circle #65

35

New! Attends Ultra Brief

Free Sample!



Aqua-Absorb core with gel-forming polymer locks wetness inside the brief! Stay-Dry liner keeps moisture away from skin. Skin stays dry and comfortable!

HDIS

Get a **Free Sample** of this ultimate brief! Simply send this coupon with $1 for postage & handling to **HDIS, 325 Paul Ave., Ferguson, MO, 63135**. Questions? Call 1-800-538-1036. Be sure to indicate the size brief you need.

___ Youth (35-75 lbs.) ___ Small (20-31" hip/waist)
___ Med. (32-44" hip/waist) ___ Lrg. (45-58" hip/waist)

Name _____
Address _____
City,State,Zip _____
Phone (_____)_____

24/38 Circle #37 Copyright 1993, HDIS.

GLOBAL EXPORT MARKETING (GEM)

Representing Exceptional Parent Internationally:
Books,
Magazines,
Information Equipment.

2 Annabelle Lane
Florham Park, NJ 07932
(201) 966-0220
Fax (201) 966-6894

Circle #87

LIFE

CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL®
THREE-OR-FOUR WHEEL, RWD SCOOTER
Choose the ride that's fit for you. ***Regal*** is available in seven models, all ergonomically designed to give your journeys freedom of choice and comfort.

BACK-SAVER™
REAR EXTERIOR WHEELCHAIR LIFT
Easy to use. No lifting. Fully automatic. Raises and stores manual wheelchairs with the turn of a key activated switch. Only 1 of 14 different Bruno Lifts.

CURB-SIDER™
SCOOTER & WHEELCHAIR LIFT
Unique 180-degree power rotation lets you pick up next to or behind your vehicle. Ideal for use in vans and trucks with liftgate or tailgate rear openings.

ELECTRA-RIDE™
STAIRWAY ELEVATOR SYSTEM
Low-cost, battery-powered stairway elevator. Needs no special wiring. Operates even if there is a power outage. To give your journeys peace of mind.

BRUNO® INDEPENDENT LIVING AIDS

Circle #8

© BRUNO INDEPENDENT LIVING AIDS, INC. 1993

CALL *1-800-882-8183* TOLL FREE OR *1-414-567-4990* FAX *1-414-567-4341*

BRUNO INDEPENDENT LIVING AIDS, INC. 1780 EXECUTIVE DRIVE PO BOX 84 OCONOMOWOC WISCONSIN 53066

Parent to Parent Programs

Parent to Parent (P–P) programs provide one-to-one emotional and informational support to parents of children who have special needs. This is done by carefully matching trained and experienced "veteran" parents with parents who are newly referred to the program. The veteran parent provides the kind of support that can only come from someone who has "been there."

The following state-by-state listing of local P–P programs was provided by The Beach Center on Families and Disabilities. For more information on P–P programs, contact the Beach Center at The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, (913) 864-7600.

ALABAMA

AIM for Infants
Auburn University
1234 Haley Ctr
Auburn, AL 36849
(205) 844-2109

Cleft Lip/Craniofacial Outreach Program
4707 Chablis Way
Birmingham, AL 35244
(205) 987-7913

Parent Network
2046 Beltline Hwy, Ste 4
Decatur, AL 35601
(205) 355-6192

Alabama Deaf-Blind Multihandicapped Association
PO Box 480204
Linden, AL 36748
(205) 295-8013

Special Ed Action Committee
PO Box 161724
Mobile, AL 36616-2274
(205) 478-1208

ARIZONA

Arizona Pilot Parents
PO Box 697
Ganado, AZ 86505
(602) 755-3411

Sharing Down Syndrome
East Side Parent Support Group
425 E Tremaine
Gilbert, AZ 85234
(602) 926-8685

Pilot Parent Partnership
2746 Holiday Dr
Lake Havasu City, AZ 86403
(602) 855-1915

Sharing Down Syndrome
Parent Support Group
3525 E Garfield
Phoenix, AZ 85008
(602) 275-1426

Pilot Parent Partnerships
2150 E Highland, Ste 105
Phoenix, AZ 85016
(602) 468-3001

Prescott Chapter, Arizona Pilot Parents
1907 Cedarwood Cir
Prescott, AZ 86301
(602) 468-3001

Graham Cty Pilot Parent Partnership
PO Box 353
Thatcher, AZ 85552
(602) 428-4731

Pilot Parents of Southern Arizona
2600 N Wyatt Dr
Tucson, AZ 85712
(602) 324-3150

Pilot Parents
PO Box 707
Whiteriver, AZ 85941
(602) 338-4325

ARKANSAS

Parent to Parent
2130 College Ave
Conway, AR 72032
(501) 327-3317

Northwest Arkansas Parent to Parent
969 Rush Dr
Fayetteville, AR 72701
(501) 521-5696

Parent to Parent
The ARC of Arkansas
2000 Main St
Little Rock, AR 72206
(501) 375-7770

CALIFORNIA

California Association for Parents of Visually Impaired
7273 Garnett St
Alta Loma, CA 91701
(909) 945-5619

Family Resource Network
PO Box 3697
Chico, CA 95927
(916) 891-5865

Parent Referral Network
PO Box 109
Eureka, CA 95502
(707) 445-8841

Exceptional Parents Unlimited
4120 N First St
Fresno, CA 93726
(209) 229-2000

Cleft Parent Guild
7120 Franklin Ave
Los Angeles, CA 90046-3002
(213) 847-3300

Parents Helping Parents
2327 Franz Hall
405 Hilgard Ave
Los Angeles, CA 90034-1563

Parent to Parent Infant Support Group
Children's Hospital of Orange Cty
PO Box 5700
Orange, CA 92613
(714) 997-3000

PROUD
PO Box 5822
Orange, CA 92613-5822
(714) 974-6419

Touchstone Support Network
378 Cambridge Ave, Ste K
Palo Alto, CA 94306
(415) 328-4495

Special Care Parents
PO Box 22322
Sacramento, CA 95822
(916) 395-2338

Parent to Parent Program of San Diego Cty
Exceptional Family Resource Ctr
8334 Clairemont Mesa Blvd, Ste 110
San Diego, CA 92111
(619) 268-8252

Bay Area Cleft Palate Awareness Coalition
2360 Clay St, Ground Fl
San Francisco, CA 94115
(415) 923-3306

Parents Helping Parents
535 Race St, Ste 140
San Jose, CA 95126
(408) 288-5010

Parent To Parent Programs

Matrix: Parent Network and Resource Center
555 Northgate
San Rafael, CA 94903
(415) 499-3877

Family Support Network
1800 N Bush St, Ste 201
Santa Ana, CA 92706
(714) 836-5511

Family Support Network
3010 W Harvard St, #D
Santa Ana, CA 92704-3914

Circle of Hope
1015 Cedar St
Santa Cruz, CA 95060
(408) 335-7404

Valley Parents Support Group
PO Box 5973-272
Sherman Oaks, CA 91413
(818) 902-1616

DIRECT Link for the DisABLED
PO Box 1036
Solvang, CA 93463
(805) 688-1603

AVENUES
PO Box 5192
Sonora, CA 95370
(209) 928-3688

Cleft Parent Guild
14764 Nanry St
Whittier, CA 90604
(310) 874-3300

COLORADO

Sturge-Weber Foundation
PO Box 460931
Aurora, CO 80046
(800) 627-5482

SKIP of Colorado
930 S Kittredge Way
Aurora, CO 80017
(303) 368-8733

Child Language Ctr, Univ of CO
CB-409, Dept CD-55
Boulder, CO 80302
(303) 492-5375

PEAK Parent Ctr
6055 Lehman Dr, #101
Colorado Springs, CO 80918
(719) 531-9400

Bridges
7475 Dakin, Ste 635
Denver, CO 80221
(303) 428-0310

Colorado Cleft Palate Association
755 S Clay St
Denver, CO 80219
(303) 934-4710

Little People of America
Front Range Chapter
7117 E Euclid Dr
Englewood, CO 80111
(303) 740-8555

Effective Parents Project
255 Main St
Grand Junction, CO 81501
(303) 241-4068

Parents Reaching Out
710 Kipling, #303
Lakewood, CO 80215
(303) 238-0240

Mile High Down Syndrome Association
PO Box 620847
Littleton, CO 80162
(303) 797-1699

Parent-Professional Partnership
1077 Laurie Cir
Meeker, CO 81641
(303) 878-3491

Parents as Partners in Special Ed
11130 Harris Way
Thornton, CO 80233
(303) 452-5958

CONNECTICUT

Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355

Western Connecticut Association for Human Rights
11 Lake Ave Ext
Danbury, CT 06811
(203) 792-3540

Connecticut Cleft Lip and Palate Parent Group
10 Starr Pl
East Hampton, CT 06424
(203) 267-4816

Lower Fairfield Cty Parent to Parent
ARC of Greenwich
50 Glenville St
Greenwich, CT 06831
(203) 329-1721

Parents Available to Help
830 Elm St
New Haven, CT 06511
(203) 488-9640

Parent to Parent Network of CT
The Family Center
181 E Cedar St
Newington, CT 06111
(203) 667-5288

Oxford Special Ed Support
10 White Gate Rd
Oxford, CT 06483
(203) 426-7649

Connecticut Traumatic Brain Injury Association
1800 Silas Deane Hwy, Ste 224
Rocky Hill, CT 06067
(203) 721-8111

Parent Sharing
PO Box 254
West Simsbury, CT 06092
(203) 282-0280

NAMI CAN of Woodbridge
8 Country Club Dr
Woodbridge, CT 06525
(203) 397-9269

DELAWARE

Parent Information Center of Delaware
700 Barksdale Rd, Ste 6
Newark, DE 19711
(302) 366-0152

DISTRICT OF COLUMBIA

Easter Seal Society
2800 13th St NW
Washington, DC 20009
(202) 232-2342

FLORIDA

Neo-Care
PO Box 160683
Altamonte Springs, FL 32716
(407) 263-4317

Gold Coast Down Syndrome Organization
22626 SW 65 Terrace
Boca Raton, FL 33428
(407) 451-2163

Parent to Parent of Pinellas Cty
1998 Sun Tree Blvd
Clearwater, FL 34623-4339
(813) 461-3614

Parent to Parent of Wakulla Cty
R 6, Box 8814
Crawfordville, FL 32327
(904) 926-7826

Parent to Parent of Walton Cty
R 5, Box 185
Defuniak Springs, FL 32433
(904) 892-2803

Parent to Parent
FND of Broward Cty
100 S Andrews Ave
Ft. Lauderdale, FL 33301
(305) 765-6622

Lee Cty Parent to Parent
155 Bayview
Ft. Myers Beach, FL 33931
(813) 463-1090

Parent to Parent of St Lucie Cty
1901 S 11th St
Ft. Pierce, FL 34950
(407) 468-5389

NICU Parent Support Group
JHM Health Ctr, Box J-296
Gainesville, FL 100296
(904) 392-6427

Parent to Parent of Alachua Cty
4805 SW 45th St
Gainesville, FL 32608
(904) 377-1827

Parent to Parent of Polk Cty
4440 Spring Ln
Lakeland, FL 33811
(813) 646-8058

Families At Mayport are Exceptional
PO Box 205, NAVSTA
Mayport, FL 32228
(904) 246-5226

Parent to Parent
510 Eleanore St
Merritt Island, FL 32953

Parent to Parent—Hispanic
9151 SW 6th St
Miami, FL 33174
(305) 223-7379

Parent to Parent of Miami
5555 SW 93rd Ave
Miami, FL 33165
(305) 271-9797

IVH Parents
PO Box 56-1111
Miami, FL 33156
(305) 232-0381

Special Parents
409 Dixie Rd
Milton, FL 32570
(904) 432-4513

Parent to Parent of North Brevard
PO Box 526
Mims, FL 32754-0526
(407) 383-0410

Parent to Parent of Collier Cty
4875 6th Ave SW
Naples, FL 33999
(813) 455-1522

Veteran Intensive Care Parents
PO Box 2700, Ste 1N
Pensacola, FL 32513-2700
(904) 474-7656

Special Parents
PO Box 15362
Pensacola, FL 32514

Parent to Parent of Martin Cty
PO Box 162
Port Salerno, FL 34992-0162

Parent to Parent of St Lucie Cty
422 NW Concord Dr
Port St Lucie, FL 34983
(407) 878-3284

Parent To Parent Programs

Parent to Parent of Palm Beach Cty
1201 Australian Ave
Riviera Beach, FL 33404
(407) 863-3310

FACE of Sarasota
PO Box 1424
Sarasota, FL 34230
(813) 349-5484

Special Beginnings c/o NICU
Sarasota Memorial Hospital
1700 S Tamiami Trail
Sarasota, FL 34329-3555
(813) 952-2470

Family Network on Disabilities of Manatee/Sarasota
350 Braden Ave
Sarasota, FL 34243
(813) 355-7637

Parent to Parent of Hernando Cty
7158 Toledo Rd
Spring Hill, FL 34606
(904) 683-6602

Tallahassee Parent Care
1300 Miccosukee
Tallahassee, FL 32303-6594
(904) 893-5518

Big Bend EH/SED Parent to Parent
319 Fairfield Ave
Tallahassee, FL 32301
(904) 539-5099

Parent/Infant Program
3528 Carrington Pl
Tallahassee, FL 32303
(904) 487-7515

Family Network on Disabilities
5510 Gray St, Ste 220
Tampa, FL 33624
(813) 289-1122

Hillsboro Parent to Parent
8905 Oren Ave
Tampa, FL 33614-1830
(813) 289-8967

GEORGIA

Parent to Parent of Georgia
2939 Flowers Rd S, Ste 131
Atlanta, GA 30341
(404) 451-5484

HAWAII

Family Support Services
1319 Punahou St, Bingham 211
Honolulu, HI 96826
(808) 973-8511

Hawaii Down Syndrome Congress
419 Keoniana St, #804
Honolulu, HI 96815
(808) 949-1999

IMPACT
49 Ihea Pl
Pukalani, HI 96788
(808) 572-7225

IDAHO

Parents Reaching Out to Parents
2195 Ironwood Ct
Coeur d'Alene, ID 83814
(208) 769-1409

Parent to Parent of Idaho Falls
201 H St
Idaho Falls, ID 83402
(208) 522-3532

Parent to Parent
2714 8th Ave
Lewiston, ID 83501
(208) 746-8599

Idaho Autism Association
2470 Warren Ave
Twin Falls, ID 83301
(208) 734-7279

ILLINOIS

Archway Services for Children
1108 W Willow
Carbondale, IL 62959
(618) 549-4442

Developmental Services Center
1304 W Bradley
Champaign, IL 61821
(217) 356-9176

Keshet—Jewish Parents of Children with Special Needs
3525 W Peterson, T-17
Chicago, IL 60659
(312) 588-0551

Illinois Next Steps, Parents Reaching Parents
100 W Randolph, Ste 8-100
Chicago, IL 60601
(800) 233-3425

Chicago Family Support Pilot Project
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(312) 939-3513

South Metropolitan Association for Low Incidence Handicapped
800 Governor's Hwy
Flossmoor, IL 60422
(708) 333-7812

Central Illinois Down Syndrome Organization
PO Box 595
Normal, IL 61761
(309) 452-3264

Parent Infant Connection—Metcalf Laboratory School
Special Ed Dept
Illinois State University
Normal, IL 61761
(309) 438-2753

National Association for Down Syndrome
PO Box 4542
Oak Brook, IL 60522-4542
(708) 325-9112

Very Important Pregnancy Program
PO Box 11085
Rockford, IL 61126
(815) 398-1451

INDIANA

First Step Early Intervention
New Horizons
PO Box 98
Batesville, IN 47006-0098
(812) 934-4528

Connection for Special Kids
692 ESR 218
Berne, IN 46711
(219) 589-3543

NEO FIGHT
4363 Idlewild Ln
Carmel, IN 46033
(317) 843-0850

Down Syndrome Support Association of Central Indiana
10792 Downing St
Carmel, IN 46033-3869
(317) 574-9757

Passages Children's Services
PO Box 1005
Columbia City, IN 46725
(219) 244-7688

Disabilities Services
PO Box 808
Crawfordsville, IN 47933
(317) 362-4020

Michiana Chapter, National SIDS Foundation
418 Constitution Ave
Elkhart, IN 46516
(219) 533-0266

Cleft Lip and Palate Support Group
1609 California Ave
Fort Wayne, IN 46805
(219) 426-1258

Down Syndrome Association of NW Indiana
2927 Jewett Ave
Highland, IN 46322
(219) 838-3656

MDA Support Group of Central Indiana
2110 E 65th St
Indianapolis, IN 46220
(317) 257-6598

Indiana Parent Information Network
4755 Kingsway Dr, Ste 105
Indianapolis, IN 46205
(317) 257-8683

Parents Support Network, Hemophilia of Indiana
1100 Burdsal Pkwy
Indianapolis, IN 46208
(317) 924-6208

TOUCH Wabash Center
2000 Greenbush St
Lafayette, IN 47904
(317) 423-5531

Everybody Counts
6701 Broadway, Ste B
Merrillville, IN 46410
(219) 769-5055

ROOTS-WINGS Parent Involvement
New Hope Services, Kids Place
1642 W McClain
Scottsburg, IN 47170
(812) 752-4892

Down Syndrome Family Support
PO Box 6579
South Bend, IN 46660
(219) 289-4831

NICU Parent, Family, Alumni Support Group
Memorial Hospital
615 N Michigan St
South Bend, IN 46601
(219) 284-7308

Knox County Advocates for Special Kids
1806 Indiana Ave
Vincennes, IN 47591
(812) 882-0375

IOWA

Family Educator Connection Program
3706 Cedar Heights Dr
Cedar Falls, IA 50613
(319) 273-8250

Pilot Parents, ARC of East Central Iowa
136 36th St Dr SE, Ste A5
Cedar Rapids, IA 52403
(319) 365-0487

Tourette Syndrome
2101 O Ave, NW
Cedar Rapids, IA 52405
(319) 396-0210

Parent To Parent Programs

Union County Pilot Parents
PO Box 57
Creston, IA 50801
(515) 782-2917

Autism Society of the Quad Cities
4712 Belle Ave
Davenport, IA 52807
(319) 359-5414

Parent Educator Connection
MPRRC, Drake Univ
Des Moines, IA 50311
(515) 271-3936

Special Care Parents
1922 E 12th St
Des Moines, IA 50316
(515) 255-5943

Patient-Parent Representative Program
Div of DD
Univ of Iowa
Iowa City, IA 52242
(319) 356-1419

Epilepsy Support Group
426 Sherrylynn Blvd
Pleasant Hill, IA 50317
(515) 263-0370

Parent-Educator Connection
102 S Main, AEA 4
Sioux Center, IA 51250
(712) 722-1931

Parent to Parent Support Group
2320 S Olive
Sioux City, IA 51106
(712) 274-2838

Parent to Parent
133 Lillian
West Des Moines, IA 52501
(515) 682-6467

KANSAS

Parent to Parent of Garden City
Box 148
Deerfield, KS 67838
(316) 426-6213

Parent to Parent of Butler Cty Special Families
1432 W Olive
El Dorado, KS 67042
(316) 321-3274

Parent to Parent of Flint Hills
1722 Yucca Ln
Emporia, KS 66801
(316) 342-6954

Parent to Parent of NW Kansas
Box 15
Gem, KS 67734
(913) 462-6857

Autism Society of Kansas
2512 N 75th St
Kansas City, KS 66109
(913) 299-2027

Parent to Parent of Douglas Cty
Rt 3, Box 56
Lawrence, KS 66044
(913) 832-1430

Parents Who Care
3312 Effingham
Manhattan, KS 66502
(913) 776-9268

Parent to Parent of NE Kansas
PO Box 307
McClouth, KS 66054
(913) 796-6319

DES Action
601 S Elm
Ottawa, KS 66067
(913) 242-4679

Parent to Parent Network, Johnson Cty
10201 Horton
Nall Hills School
Overland Park, KS 66207
(913) 967-7677

Parent to Parent of SE Kansas
3118 Corning
Parsons, KS 67357
(316) 421-6550

Salina Area Parent to Parent Program
Salina Cty Health Dept
300 W Ash, Rm 107
Salina, KS 67401
(913) 827-9376

Rubinstein-Taybi Syndrome Parent Group
414 E Kansas
Smith Center, KS 66967
(913) 282-6237

Parent to Parent, Shawnee Cty
2218 Wilmington Ct
Topeka, KS 66606-1748
(913) 235-9680

Families Together
1023 SW Gage Blvd
Topeka, KS 66604
(913) 273-6343

Parent to Parent of Sedgwick Cty
8024 S Hillside
Wichita, KS 67233
(316) 788-3092

Connecting Point
PO Box 1120
Wichita, KS 67201
(316) 943-1191

KENTUCKY

PUSH Infant and Preschool Program
PO Box 781
Frankfort, KY 40602
(502) 875-4403

Parent Outreach
1146 S Third St
Louisville, KY 40203

LOUISIANA

Neonatal Intensive Care Unit—Parents
10638 Shermoor
Baton Rouge, LA 70815
(504) 293-3562

Parent Conference on Special Ed
Louisiana Dept of Education
PO Box 94064
Baton Rouge, LA 70804-9064
(504) 342-3636

Louisiana Rett Syndrome Foundation
7629 Sailfish Dr
Lake Charles, LA 70605
(318) 474-5727

Parent to Parent of Louisiana
The Family Support Program
Children's Hospital
200 Henry Clay Ave
New Orleans, LA 70118
(504) 896-9268

Concerned Parents for Students
1022 Gulf Ln
Sulphur, LA 70663
(318) 528-2191

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338-2067
(207) 582-2504

Parent to Parent
United Cerebral Palsy of Northeastern Maine
103 Texas Ave
Bangor, ME 04401
(207) 941-2885

Mid-Coast Children's Services
11 Maple St
Rockland, ME 04841
(207) 594-8474

York Cty Parent Awareness
150 Main St
MidTown Mall
Sanford, ME 04073
(207) 324-2337

MARYLAND

Maryland Infants and Toddlers Program
Family Support Network
One Market Center, Ste 304
Baltimore, MD 21201-3446
(410) 333-8100

National Federation of the Blind Parents of Blind Children Div
1800 Johnson St
Baltimore, MD 21230
(301) 659-9314

Learning Disabilities Association
76 Cranbrook Rd, Ste 299
Cockeysville, MD 21030-3479
(301) 265-6193

Parents of Preemies
23020 Wild Hunt Dr
Gaithersburg, MD 20882
(301) 253-6534

Parents of Preemies
2822 Chasbarb Ct
Gaithersburg, MD 20879

Anne Arundel Cty Infants & Toddlers Program
160 Funke Rd
Glen Burnie, MD 21061
(410) 222-6911

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785
(301) 459-3700

Montgomery Cty ARC
11600 Nebel St
Rockville, MD 20852
(301) 984-5792

MASSACHUSETTS

Cape Ann Early Intervention
111 Dodge St
Beverly, MA 01915
(508) 927-5843

Parent to Parent of Birth Defects Services
Children's Hospital, Fegan 10
300 Longwood Ave
Boston, MA 02115
(617) 735-7037

Greater Boston Parent to Parent
1505 Commonwealth Ave
Boston, MA 02135
(617) 783-3900

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(617) 482-2915

National Tay-Sachs & Allied Diseases Association
2001 Beacon St, #204
Brookline, MA 02146
(617) 277-4463

South Shore Parent to Parent
South Shore ARC
250 Elm St
Hanover, MA 02339
(617) 335-3023

Massachusetts Down Syndrome Congress
PO Box 866
Melrose, MA 02176
(617) 742-4440

Parent to Parent
247 Smith St
New Bedford, MA 02740
(508) 966-8551

New Horizons
388 Columbus Ave Ext
Pittsfield, MA 01201
(413) 499-4537

Raynham Parent Advisory Council
687 Pleasant St
Raynham, MA 02767
(508) 822-1598

PEP Match
PO Box 1334
South Yarmouth, MA 02664
(508) 398-3866

HOLD: Helping Our Learning Disabled
10 Waycross St
Worcester, MA 01603
(508) 752-2906

MICHIGAN

Hand and Hand
PO Box 658
Bay City, MI 48707
(517) 892-4533

Parent to Parent, ARC Oakland Cty
690 E Maple
Birmingham, MI 48009
(313) 646-4522

SE Michigan Parents of Premature Infants
1680 Washington
Birmingham, MI 48009
(313) 258-6753

Training Resources Education and Networking on Down Syndrome
PO Box 1996
Holland, MI 49422-1996
(616) 392-6307

Down Syndrome Association of West Michigan
PO Box 8703
Kentwood, MI 49518

Peer Support Project
530 W Ionia St, Ste C
Lansing, MI 48933
(517) 487-9260

Peer Support Project
7039 Gra-Al Shores
Rapid River, MI 49878
(906) 474-6666

Parents of Children with Special Needs
1105 S Clinton Ave
St John's, MI 48879
(517) 224-4383

National MPS Society
3260 Old Farm Ln
Walled Lake, MI 48390
(313) 363-4412

MINNESOTA

People to People, One-to-One Support
514 N Cedar
Owatonna, MN 55060
(507) 451-0576

Midstate Pilot Parents
PO Box 1536
St Cloud, MN 56302
(612) 253-6844

Parents for Parents (NICU)
Veteran Parents (PICU)
280 N Smith Ave, Ste 245
St Paul, MN 55102
(612) 220-6731

Pilot Parents in Ramsey Cty
425 Etna St, #35
St Paul, MN 55106
(612) 778-0727

Turner's Syndrome Society of the US
768-214 Twelve Oaks Ctr
15500 Wayzata Blvd.
Wayzata, MN 55391-1416
(612) 475-9944

MISSOURI

Missouri Head Injury Association
3632-A W Truman Blvd
PO Box 84
Jefferson City, MO 65102-0084
(314) 893-2444

Pilot Parents Program
PO Box 10984
Springfield, MO 65808
(417) 883-2593

MONTANA

Parents, Let's Unite for Kids
EMC/SPED Bldg, Rm 267
1500 N 30th St
Billings, MT 59101-0298
(406) 657-2055

Quality Life Concepts
600 6th St NW
PO Box 2506
Great Falls, MT 59403
(406) 452-9531

Osteogenesis Imperfecta Foundation Peer Contact Network
PO Box 768
Manhattan, MT 59741-0768
(406) 284-6038

Parents of Children with Special Needs
School of Ed
University of Montana
Missoula, MT 59812
(406) 542-1330

NEBRASKA

Exceptional Parents Night Out Parent Support Group
4250 Shanna St
Grand Island, NE 68130
(308) 381-1709

Preschool Activities for Language and Learning Skills
ESU #9, PO Box 2047
Hastings, NE 68901
(402) 463-5611

Parent Assistance Office
310 W 24th
Kearny, NE 68847
(308) 236-6867

Pilot Parents
1707 Polk
Lexington, NE 68850
(308) 324-4428

Parents Encouraging Parents
Nebraska Dept of Ed
301 Centennial Mall S
Lincoln, NE 68509
(402) 471-2471

Pilot Parents Program, ARC-Capital
215 Centennial Mall S, #410
Lincoln, NE 68508
(402) 466-2979

League of Human Dignity
Independent Living Center
1701 P St
Lincoln, NE 68507
(402) 471-7871

Pilot Parents Program, Greater Omaha ARC
3610 Dodge St
Omaha, NE 68131
(402) 346-5220

Parent to Parent
826 Arlene Ave
Papillion, NE 68046
(402) 592-2719

NEW HAMPSHIRE

New Hampshire Special Families United
PO Box 1141
Concord, NH 03302-1141
(603) 224-2022

Treacher Collins Family Network
PO Box 5
Concord, NH 03302-0005
(603) 226-4371

Parent to Parent of New Hampshire
PO Box 622
Hanover, NH 03755
(603) 448-6393

Upper Valley Support Group
PO Box 622
Hanover, NH 03755
(603) 448-6311

NEW JERSEY

Cleft Lip and Palate Support Group
501 Douglas Dr
Cherry Hill, NJ 08034
(609) 482-6554

Parent Support, ARC Bergen-Passaic Cty
481A Edward Ross Dr
Elmwood Park, NJ 07407
(201) 797-0100

Family Support Services Program
NJ Association of the Deaf-Blind
28 Kennedy Blvd
E Brunswick, NJ 08816
(908) 249-4433

Association for Special Children and Families
Supporting Special Parents
PO Box 494
Hewitt, NJ 07421
(201) 728-8744

Down Syndrome Parent to Parent
ARC of Essex County
7 Regent St
Livingston, NJ 07039
(201) 535-1181

Association for Children with Russell-Silver Syndrome
22 Hoyt St
Madison, NJ 07940
(201) 377-4531

Parents Encouraging Parents, ARC-Morris Chapter
PO Box 123
Morris Plains, NJ 07950
(201) 326-9750

NEW MEXICO

Parents Reaching Out, Alamogordo
PO Box 3631, BRS-A
Alamogordo, NM 88311
(505) 437-9290

Parents of Preterm Infants Network
Univ of New Mexico Hospital
Dept of Pediatrics
Albuquerque, NM 87131
(505) 277-3946

Parent To Parent Programs

Parents for Behaviorally Different Children
1720 Louisiana NE, Ste 204
Albuquerque, NM 87110
(505) 265-0430

PRO Parent to Parent Network
1127 University NE
Albuquerque, NM 87102
(505) 842-9045

PRO Parent Support Network
4106 Winchester
Las Cruces, NM 88001
(505) 522-5669

NEW YORK

Parent-Friend: One to One
New York Easter Seal Society
845 Central Ave
Albany, NY 12206
(518) 438-8785

Newborn & Family Support Services Network
North Central Bronx Hosp
3424 Kossuth Ave
Bronx, NY 10467
(718) 519-4797

Headway for Brain Injured
856 Ridge Rd
Buffalo, NY 14141
(716) 822-2261

Prader-Willi Alliance of New York
40 Holly Ln
East Hills, NY 11577
(516) 621-2445

Levittown Hydrocephalus Support Group
Satellite Information Ctr
59 Market Ln
Levittown, NY 11756

Young Adult Institute
New York League for Early Learning
460 W 34th St
New York, NY 10001
(212) 563-7474

The Jewish Guild for the Blind
Downstate Resource Network
15 W 65th St
New York, NY 10023
(212) 769-6327

Parents of Special Children
PO Box 5357
Oswego, NY 13126
(315) 343-6480

Parent Assistance Committee on Down Syndrome
208 Lafayette Ave
Peekskill, NY 10566
(914) 739-4085

St Charles Early Intervention Program
501 Myrtle Ave
Port Jefferson, NY 11777
(516) 331-6400

Parents Available to Help
Special Care Nursery
Vassar Hospital
Poughkeepsie, NY 12601
(914) 454-8500

The Family Connection
Family Resource Center/WIHD
121-C Cedarwood Hall
Valhalla, NY 10595
(914) 285-1343

Parent to Parent
239 Champion Ave
Webster, NY 14580
(716) 265-3778

NEVADA

Nevada Specially Trained Effective Parents
6200 W Oakey
Las Vegas, NV 89102
(702) 870-7050

Nevada Parent Network
University of Nevada, Reno
REPC, College of Education/278
Reno, NV 89557-0082
(702) 784-4921

NORTH CAROLINA

Parent to Parent
Rt 2, Box 178-A
Angier, NC 27501
(919) 639-0172

Parents Reaching Out to Parents of Children with Special Needs
PO Box 638
Biscoe, NC 27209

Family Support Network of The High Country
Appalachian State Univ
Edwin Duncan Hall
Boone, NC 28608
(704) 262-6089

Parent Support Group
63 N Canton Rd
Canton, NC 28716
(704) 452-4397

Family Support Network—Orange, Durham, Chatham Ctys
UNC Chapel Hill
CB#7340, Chase Hall
Chapel Hill, NC 27599
(919) 966-2841

University of North Carolina Craniofacial Center
School of Dentistry
Chapel Hill, NC 27599-7450
(919) 966-2275

Family Support Network of North Carolina
CB #7340
University of North Carolina
Chapel Hill, NC 27599
(919) 966-2841

Family Support Network of Metrolina
PO Box 35466
Charlotte, NC 28235
(704) 563-6111

Family Support of the Albemarle
1601 Forest Dr
Elizabeth City, NC 27909
(919) 338-6987

Cape Fear Association of Parents Helping Parents
3403 Melrose Rd
Fayetteville, NC 28304
(919) 486-1605

Family Support Network
1623 N Webb St
Gastonia, NC 28052
(704) 854-4839

Family Support Network, Goldsboro
719 East Ash St
Goldsboro, NC 27530
(919) 580-0330

Family Support Network of Greater Greensboro
Womens Hospital of Greensboro
801 Green Valley Rd
Greensboro, NC 27408
(919) 574-6507

Family Support Network of Eastern North Carolina
Irons Bldg, ECU Campus
Greenville, NC 27858
(919) 757-4494

Western Carolina Parents of EC Henderson County
PO Box 1454
Hendersonville, NC 28793
(704) 685-3336

Special Families Support Group
Catawba County Mental Health
Rt 3, Box 339
Hickory, NC 28602
(704) 326-5909

Family Support Network/ Hope Network
4051 4th St, NW
Hickory, NC 28601
(704) 328-9496

Tri Cty Local Unit/Autism Society of NC
Rt 2, Box 314
Hickory, NC 28601
(704) 256-5242

Family Support Network of Catawba Cty
2740 6th St NE
Hickory, NC 28601
(704) 327-4857

Parent Support Group
YMCA
112 Gatewood
High Point, NC 27262
(910) 882-4126

Family Support Network of Davidson Cty
36 Vance Cir
Lexington, NC 27292
(704) 246-4105

Parents Resource Organization
Rt 2, Box 430
Mocksville, NC 27028
(919) 998-3311

HOPE: Helping Other Parents Through Empathy
300 Enola Rd
Morganton, NC 28655
(704) 433-2877

Family Support Network of the Neuse Area
1405 S Glenburnie Rd
New Bern, NC 28562
(919) 633-0242

Parents Encouraging Parents
PO Box 1318
Pisgah Forest, NC 28768
(704) 884-5649

Family Support Network of Wake Cty
11304 Coachman's Way
Raleigh, NC 27614
(919) 848-7838

Caring Parents
1506 Laurel St
Roanoke Rapids, NC 27870
(919) 535-5887

Parent Program
Rt 4, Box 1555E
Rutherfordton, NC 28139
(704) 245-0711

Tuberous Sclerosis Connection
NC Tuberous Sclerosis Association
1005 Indianhead Cir
Snow Hill, NC 28580
(919) 747-8592

Family Support Network
Rt. 11, Box 369A
Statesville, NC 28677
(919) 876-4621

Parent Support Group
257 Long Chapel Rd
Weaverville, NC 28787
(704) 645-3546

Family Support Network of SE North Carolina
DEC, 1501 Dock St
Wilmington, NC 28401
(919) 251-5817

Parents Together
4505 Shattalon Dr
Winston-Salem, NC 27106
(919) 924-5301

NORTH DAKOTA

Family First: Education for Empowerment
PO Box 1883
Jamestown, ND 58402
(701) 252-2847

OHIO

Tracheostomy Support Group
Children's Hospital
144 Elmwood St
Barberton, OH 44203
(216) 745-4392

Parent to Parent Support
814 West St
Caldwell, OH 43724
(614) 732-5188

Down Syndrome Association of Greater Cincinnati
Parent Listener Program
1821 Summit Rd, Ste 102
Cincinnati, OH 45237
(513) 761-5400

Ohio Protection and Advocacy
8625 Denallen Dr
Cincinnati, OH 45255
(513) 474-2385

Family First
1821 Summit Rd, G-30
Cincinnati, OH 45237
(513) 821-3533

Parent Connection, Cleveland
Regional Perinatal Network
11001 Cedar Ave
Cleveland, OH 44106
(216) 844-3391

The Family Information Network
246 N High St, 4th Fl
Columbus, OH 43266-0118
(614) 644-8389

Family First
2917 Sherwood Rd
Columbus, OH 43209
(614) 228-4333

The Ohio Head Injury Association
1335 Dublin Rd, Ste 50-A
Columbus, OH 43215-1000
(614) 481-7100

Celebrating Families of Children/ Adults with Special Needs
16 Vassar Dr
Dayton, OH 45406
(513) 275-0990

Special Needs Information Ctr
PO Box 87
Girard, OH 44420
(216) 545-2837

Miami Valley Down Syndrome Association
1444 Beaver Creek Ln
Kettering, OH 45429-3704
(513) 294-1240

NTSA State Rep. Coordinator
3006 Plum Creek Pkwy
Medina, OH 44256
(301) 459-9888

Families in Touch
Mental Health Assn of Licking Cty
65 Messimer Dr
Newark, OH 43055
(614) 522-1351

Family Information Network of NW Ohio
1 Stranahan Sq, #540
Toledo, OH 43604
(419) 242-9587

OKLAHOMA

Parents of Children with Down Syndrome
R 3, Box SA-65
Tuttle, OK 73089
(405) 680-7151

OREGON

Parent Network Program
ARC of Lane Cty
45 W Broadway, Ste 205
Eugene, OR 97401
(503) 343-5256

Caring Parents
2825 Barnett Road
Medford, OR 97504
(503) 773-6281

NICU Parent Support Group
Rogue Valley Medical Ctr
2825 Barnett Rd
Medford, OR 97504
(503) 770-4233

Parents Supporting Parents
6901 SW 8th Ave
Portland, OR 97219
(503) 244-6719

Pilot Parent Program, Tri Cty
718 W Burnside, #316
Portland, OR 97212
(503) 223-7279

Oregon COPE Project
999 Locust St NE
Salem, OR 97303-5299
(503) 373-7477

PENNSYLVANIA

Family Outreach
836 E 15th St
Chester, PA 19013
(215) 872-6313

Brain Injury Support Groups, Heading On
595 W State St
Doylestown, PA 18901
(215) 345-2636

Parent Support Center
252 Waterford St
Edinboro, PA 16412
(814) 734-5610

Living Unlimited
UHRC
Penn State Univ
Elizabethtown, PA 17022
(717) 367-1161

Westmoreland Cty Parent to Parent
1228 Brinkerton Rd
Greensburg, PA 15601
(412) 832-1063

Down Syndrome Support Group of Lancaster Cty
c/o S June Smith Ctr
23 N West End Ave
Lancaster, PA 17603
(717) 299-4829

Hemifacial Microsomia/ Goldenhar Syndrome Family Support Network
6 Country Lane Way
Philadelphia, PA 19115
(215) 677-4787

Intensive Caring Unlimited
910 Bent Ln
Philadelphia, PA 19118
(215) 233-4723

Parent Specialist Education Program
2350 W Westmoreland St
Philadelphia, PA 19140
(215) 229-4550

Parent to Parent
1001 Brighton Rd
Pittsburgh, PA 15233
(412) 322-6008

Parent to Parent
PO Box 322
Temple, PA 19560

Charcot-Marie-Tooth Association
601 Upland Ave
Upland, PA 19015
(215) 499-7486

N Central Pennsylvania Head Injury Network
777 Rural Ave
Williamsport, PA 17701
(717) 321-2660

RHODE ISLAND

Parents Reaching Out
1 Simmons Road
Barrington, RI 02806
(401) 245-5241

Down Syndrome Society of Rhode Island
99 Bald Hill Rd
Cranston, RI 02920
(401) 463-5751

Parent Support Network
855 Waterman Ave, Ste D
East Providence, RI 02914
(401) 431-1240

Parent Training Program
Special Ed Program Services Unit
22 Hayes St
Providence, RI 02908
(401) 277-3505

Central Region Early Intervention
3445 Post Rd
PO Box 7789
Warwick, RI 02887-7789
(401) 739-2700

SOUTH CAROLINA

Family Support Program
Charles Webb Easter Seals Ctr
325 Calhoun
Charleston, SC 29401
(803) 723-7224

Family Connection of SC
2712 Middleburg Dr, Ste 103-B
Columbia, SC 29204
(803) 252-0914

National Information Clearinghouse for Infants with Disabilities
CDD, Benson Bldg, 1st Fl
Columbia, SC 29208
(800) 922-9234

TENNESSEE

Project ECHO-ETSU Center for Early Childhood
PO Box 15, 520-A
Johnson City, TN 37614-0002
(615) 929-5662

Tennessee Infant-Parent Service for Hearing Impaired
2725 Island Home Blvd
Knoxville, TN 37920
(615) 579-2456

Parents and Post Op
801-A Teaberry Ln
Knoxville, TN 37919
(615) 691-2418

Wee Care
6019 Walnut Grove
Memphis, TN 38119
(901) 766-5023

Parent To Parent Programs

Parents of Special Children
PO Box 3196
Murfreesboro, TN 37133
(615) 849-1225

Parents Reaching Out
203 Burlington
Nashville, TN 37215
(615) 297-8129

TEXAS

Pilot Parents
2818 San Gabriel
Austin, TX 78705-3598
(512) 476-7044

Parent Care of Austin
1603 E 38½ St
Austin, TX 78722
(512) 472-8351

Partners Resource Network
277 N 18th St #2
Beaumont, TX 77707
(409) 838-2366

Down Syndrome Guild
PO Box 821174
Dallas, TX 75382-1174
(214) 239-8771

Project KIDS
Dallas Ind. School District
12532 Nuestra
Dallas, TX 75130
(214) 490-8701

Tarrant Cty Society for Hearing Impaired Infants & Youth
6416 Canyon Cir
Fort Worth, TX 76133
(817) 346-0421

Parent to Parent
3201 Ridgeview Ln
Irving, TX 75062
(214) 255-7815

Partners Resource Network
12602 Moss Hollow Ct
Live Oak, TX 78233
(512) 599-0719

Developmental Education Birth to Two
1628 19th St
Lubbock, TX 79413
(806) 766-1172

Parent Case Management Program
3001 S Jackson
San Angelo, TX 76904
(915) 949-9535

Craniofacial Anomaly Support Association
3501 Oakhorne Dr
San Antonio, TX 78247
(512) 496-0270

Parent Helpline
PO Box 7330, Station A
San Antonio, TX 78285
(512) 228-2222

UTAH

Graduate Parents—Primary
Children's Medical Ctr (NICU)
100 N Medical Dr
Salt Lake City, UT 84113-1100
(801) 588-3899

Parent to Parent
Univ of Utah Hospital
50 North Medical Dr, Rm 2553
Salt Lake City, UT 84132
(801) 581-2098

HOPE—A Parent to Parent Network
2290 E 4500 S, Ste 110
Salt Lake City, UT 84117
(801) 272-1051

VERMONT

Vermont Interdisciplinary Team for Intensive Special Ed
Center for DD/UAP
Univ of Vermont 499C
Waterman Bldg
Burlington, VT 05405-0160
(802) 656-4031

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(802) 649-3020

Parent to Parent of Vermont
1 Main St
69 Champlain Mill
Winooski, VT 05404
(802) 655-5290

VIRGINIA

Southwest Virginia Parent to Parent
Developmental Services
Drawer II
Big Stone Gap, VA 24219
(703) 523-0682

Craniofacial Anomalies Clinic
UVA Medical Ctr
Box 376
Charlottesville, VA 22908
(804) 924-5801

Human Growth Foundation
7777 Leesburg Pike, Ste 202S
Falls Church, VA 22043
(800) 451-6434

Harrisonburg-Rockingham Parent to Parent
1251 Smithland Rd
Harrisonburg, VA 22801
(703) 433-5821

Twin Cty/Galax Parent to Parent
PO Box 931
Hillsville, VA 24343
(703) 236-2122

Parent to Parent of Southside Virginia
2008 Wakefield St
Petersburg, VA 23805
(804) 862-9940

Parent to Parent, Family and Children's Service
1518 Willow Lawn Dr
Richmond, VA 23230
(804) 282-4255

Parent to Parent, Roanoke Valley
3020 Mansfield St
Roanoke, VA 24012
(703) 366-3551

Parent to Parent Support Group
2110 Avenel Ave
Roanoke, VA 24015
(703) 774-3636

Parents of Children with Down Syndrome
451 Orchard St
Vienna, VA 22180
(703) 281-1211

WASHINGTON

Parent to Parent
c/o WCEL
1101 State St
Bellingham, WA 98225
(206) 671-3660

Parent to Parent, Kitsap Cty
The ARC of Kitsap Cty
3232 N Perry
Bremerton, WA 98310
(206) 377-3473

Parent to Parent, Lewis Cty
Infant/Toddler Development Ctr
156 NW Prindle
Chehalis, WA 98532
(206) 748-4359

Parent to Parent, Whitman/Garfield/Asotin Ctys
1452 Highland
Clarkston, WA 99430
(509) 758-9420

Parent to Parent, Snohomish Cty
The ARC Of Snohomish Cty
PO Box 602
Everett, WA 98206
(206) 258-2459

Parent to Parent, Whatcom Cty
3778 Aldergrove Rd
Ferndale, WA 98248
(206) 366-3728

Parent to Parent, Garys Harbor Cty
722 Queen Ave
Hoquiam, WA 98550
(206) 533-2187

Parent to Parent, Cowlitz/Wahkiakum Ctys
The ARC of Cowlitz Valley
1129 Broadway
Longview, WA 98632
(206) 425-5494

Parent to Parent, Grant/Adams/Lincoln Ctys
903 W 3rd
Moses Lake, WA 98837
(509) 765-3686

Parent to Parent, Skagit Cty
PO Box 1833
Mount Vernon, WA 98273
(206) 757-7048

Parent to Parent, Island Cty
3597 350th Ave W
Oak Harbor, WA 98277
(206) 675-1409

Parent to Parent, Thurston Cty
1703 E State St
Olympia, WA 98506
(206) 352-1126

Parent to Parent, Okanogan Cty
PO Box 3051
Omak, WA 98841
(509) 826-0716

Parent to Parent, Clallam Cty
2039 W 10th St
Port Angeles, WA 98362
(206) 457-1282

Parent to Parent Support Program
1009 Georgiana St
Port Angeles, WA 98362
(206) 457-8355

Parent to Parent, Jefferson Cty
1435 Corona St
Port Townsend, WA 98368
(206) 385-7666

Parent to Parent, Benton/Franklin Ctys
The ARC of Tri-Cities
767 Williams Blvd
Richland, WA 99352
(509) 943-2908

Parent to Parent Programs State Office
The ARC-King Cty
10550 Lake City Way NE, Ste A
Seattle, WA 98125-7752
(206) 948-7322

Parent to Parent, King Cty
10550 Lake City Way NE, Ste A
Seattle, WA 98125-7752
(206) 364-4645

The Cleft Connection c/o CSHCN
Seattle-King County Health Dept
110 Prefontaine Pl S, Ste 500
Seattle, WA 98104
(206) 296-4665

Parent to Parent, Mason Cty
SE 290 Alpine Ave
Shelton, WA 98584
(206) 426-1005

Parent to Parent, Spokane Cty
The ARC of Spokane Cty
W 127 Boone Ave
Spokane, WA 99201
(509) 244-4499

Parent to Parent, Pierce Cty
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741

Parent to Parent, Clark Cty
The ARC of Clark Cty
PO Box 2608
Vancouver, WA 98668
(206) 254-1562

Parent to Parent, Walla Walla/Pacific Ctys
Dept of Human Services
PO Box 1595
Walla Walla, WA 99362
(509) 527-3278

Parent to Parent, Chelan/Douglas Ctys
PO Box 1
Wenatchee, WA 98807
(509) 782-4476

Parent to Parent, Yakima/Kittitas Ctys
603 S 18th Ave
Yakima, WA 98902
(509) 452-1382

WEST VIRGINIA

Autism Services Ctr
Pritchard Bldg, Ste 907
605 9th St
PO Box 507
Huntington, WV 25710-0507
(304) 525-8014

West Virginia Head Injury Fdn
PO Box 574
Institute, WV 25112-0574
(304) 766-4892

WISCONSIN

Pilot Parents
R 2, Box 434
Ashland, WI 54806
(715) 682-7171

Mothers United for Moral Support
150 Custer Ct
Green Bay, WI 54301
(414) 336-5333

D.E.A.F.
PO Box 23825
Green Bay, WI 54305-5825
(414) 437-7531

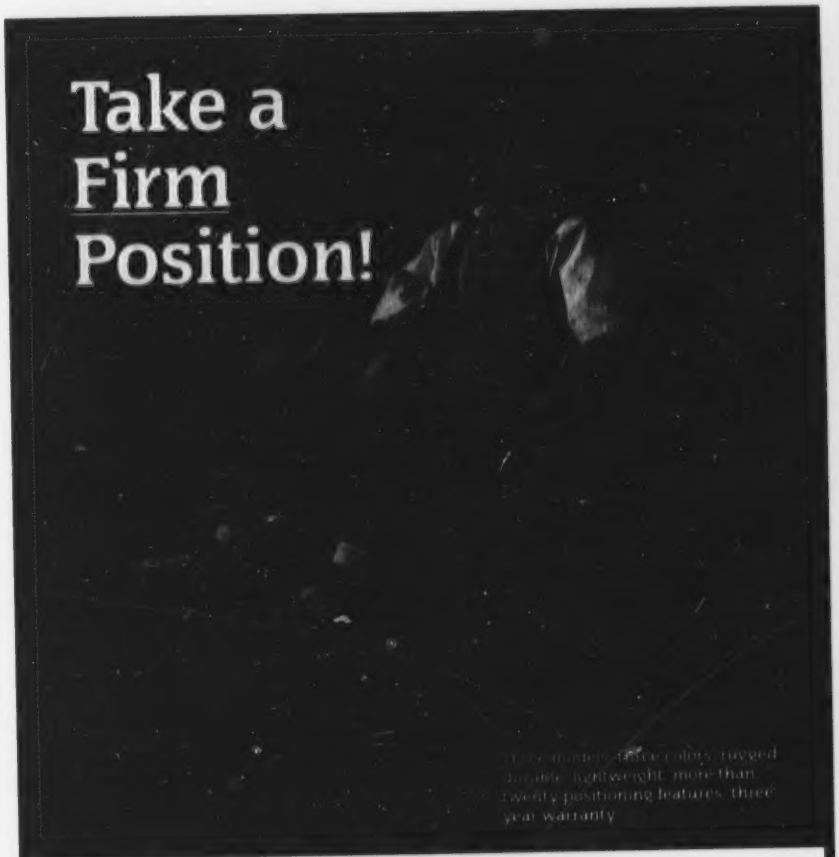
Brown County ARC
PO Box 12770
Green Bay, WI 54307-2770
(414) 498-2599

Wee-Life Parents
216A S Main St
PO Box 193
Lodi, WI 53555
(608) 592-4648

Cleft Lip and Palate Helpline
2808 E Newton Ave
Milwaukee, WI 53211
(414) 962-1053

SW Wisconsin Parents of Down Syndrome Persons
18716 W Mound Rd
Platteville, WI 53818
(608) 348-8906

Parent to Parent
ARC
818 6th St
Racine, WI 53403
(414) 634-6303



"Convaid Cruisers" . . . firm positioning buggies for children with special needs.

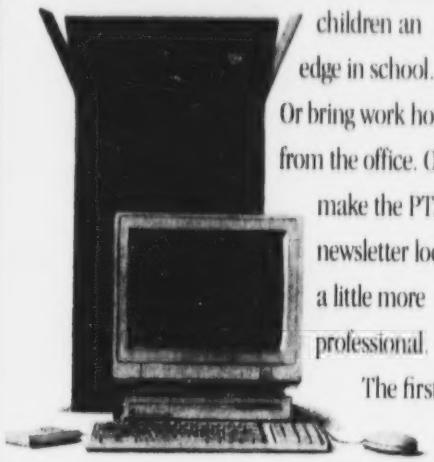
Your child's comfort is assured by the care and construction that goes into every Convaid Cruiser because the patented fold of the Cruiser *gives your child firm positioning*. In fact, the more your child's body weight presses down, the firmer the upholstery becomes. When you travel, the Cruiser folds easily to fit into your trunk or backseat.

Convaid PRODUCTS INC
P.O. Box 2458 / Palos Verdes, California 90274
310-539-6814 / 1-800-552-1020 TOLL FREE
FAX 310-539-3670
Circle #16

How to buy your first personal computer.

This year, millions of families just like yours will decide to take home their very first personal computer.

You might be looking to give your children an edge in school. Or bring work home from the office. Or make the PTA newsletter look a little more professional.



A computer should be easy to buy. So Macintosh Performa puts everything your family needs in one box.

The first step in finding the right computer is to ask a few simple questions.

What do you really need in a computer?

You can plunge into books thicker than the Peoria white pages to find the answer, immersing yourself in the megabytes and whosiwhatzits of computer terminology just to figure out your choices.

Or, you can look into a new kind of personal computer: Performa. The family Macintosh.

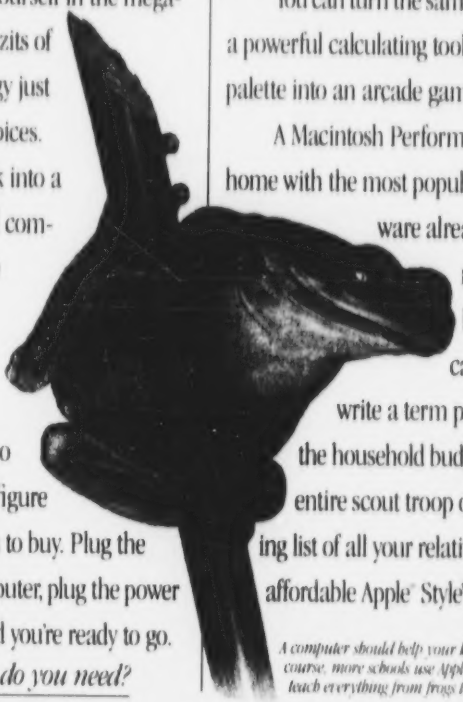
We started by putting everything together in one box, so you wouldn't have to figure out what components to buy. Plug the monitor into the computer, plug the power cord into the wall, and you're ready to go.

What software do you need?

The magic of a personal computer is that you can change what it does simply by changing the software.

You can turn the same computer from a powerful calculating tool into an artist's palette into an arcade game.

A Macintosh Performa arrives in your home with the most popular kinds of software already installed. So right out of the box, your family can do things like write a term paper, calculate the household budget, organize an entire scout troop or keep a mailing list of all your relatives. (Plug in an affordable Apple® StyleWriter™ II printer, and all these projects take on the professional look of typeset documents.)



A computer should help your kids to learn. Of course, more schools use Apple computers – to teach everything from frogs to Flaubert.

A computer should protect your investment. Performa makes it easy to grow as your family's needs grow, to let you add new capabilities and take advantage of future innovations.

Of course, Performa also gives you the power to run thousands of other programs you can buy. If you use a computer at work, many of those same programs are available for the Macintosh Performa (from Lotus 1-2-3 to WordPerfect). And it lets your kids run many of the same software programs used in schools (more schools use Apple computers than any other brand).

Support and limited warranty apply to Apple Macintosh CPUs and peripherals only. Support does not apply to third party software. © 1994 Apple Computer, Inc. All rights reserved. Apple, the Apple logo, Macintosh,

A computer should be easy to set up. So a Macintosh Performa requires no tools – not even one of these.

Will everybody in the family be able to use it?

It doesn't matter how powerful a computer is if your family can't figure out how it works. Fortunately, Performa combines enough power to run a whole business with the practical simplicity of a Macintosh.

Performa even includes special software called At Ease™ that makes it easy for very young children to use.

Other computers may look simple in the store. But if you click the wrong button, you could find yourself staring at complex computer codes.

Are there any hidden costs?

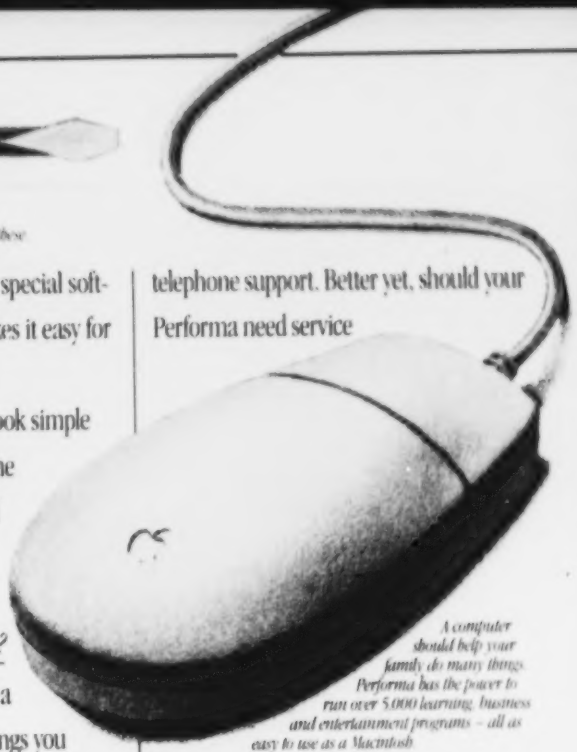
Often, the base price of a computer doesn't include things you really need or want as soon as you get your computer home.

You may have to pay extra for basic things like sound and graphics. You may have to buy software separately. You may even have to pay extra for a keyboard, a mouse and a color monitor.

With Performa, all of these things are included for one affordable price. Every Performa model even includes a fax/modem.

Where can you get help if you need it?

Even with the easiest computer, you may have a few questions now and then. So every Performa includes unlimited toll-free telephone support. Better yet, should your Performa need service in the first year, we'll come to you.*



A computer should help your family do many things. Performa has the power to run over 5,000 learning, business and entertainment programs – all as easy to use as a Macintosh.

The built-in fax/modem even lets you send a fax directly from your desk to a fax machine (or connect, via telephone, to services like America Online and Prodigy).

The whole idea is to make owning a personal computer an incredibly satisfying experience. To find out how easy it can actually be, call us at 800-538-9696, ext. 215. We'll give you the name and number of a Performa retailer near you. Then you'll discover the most important power a personal computer can bring your family. The power to be your best.

A computer should give you confidence. So Macintosh Performa includes a year of in-home service and unlimited toll free telephone help.

Performa

The Family Macintosh

Performa, StickWriter and "The power to be your best" are registered trademarks of Apple Computer, Inc. At Ease is a trademark of Apple Computer, Inc. This ad was created using Macintosh personal computers.

Children's laughter is music to our ears.

Our dedicated staff at the Kennedy Krieger Institute is devoted to helping children and adolescents with physical, mental or educational disabilities. Through diagnosis, treatment and education, we can help find the key that unlocks the future for your child and your family.

Kennedy Krieger Institute... providing quality services for youngsters of any age with:

- Assistive Technology Needs
- Motor and Language Delays
- Metabolic & Degenerative Disorders
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

Kennedy Krieger Institute

A comprehensive resource for children with disabilities

Call us to talk about your concerns, slight or severe. We can help.

(410) 550-9400/1-800-873-3377
707 North Broadway
Baltimore, MD 21205

Circle #45

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

Circle #26

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

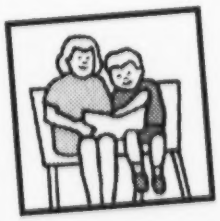
equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

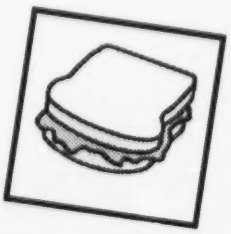
Circle #25

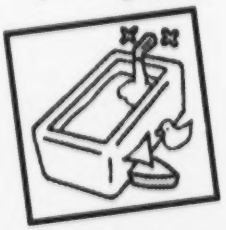
imaginart

Let us help you and your child with friendly, high quality materials:



- picture communication
- feeding and swallowing
- language development *featuring the Hanen Program*
- toys and games to train daily living skills





Pictures shown are communication stickers from our Pick 'n Stick Primary Pack.

Call or write for our free catalog:
Imaginart Communication Products
307 Arizona Street, Dept. EP4, Bisbee, AZ 85603
(800) 828-1376

Circle #41

Alliance for Technology Access Centers

The Foundation for Technology Access (FTA) began in 1987 as a joint project of a grass-roots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer.

From a small group of parents, consumers and professionals, FTA has grown to become one of the nation's largest resources for helping adults and children with disabilities gain access to the benefits of adaptive technology.

FTA's most important means of promoting technology access may be its Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use.

Individual centers may also offer additional services. The following pages provide an up-to-date directory of ATA centers, with a description of the specific services offered by each.

ALABAMA

Birmingham Alliance for Technology Access Center
Birmingham Independent Living Ctr
206 13th St S
Birmingham, AL 35253-1317
(205) 251-2223/0863
(205) 251-0605 (FAX)
AppleLink: BILC
1,2,3,4,5,7,8,9,10,11,14,15,16,17

Technology Assistance for Special Consumers
PO Box 443
Huntsville, AL 35804
(205) 532-5996
AppleLink: TASC
1,2,3,4,5,7,8,9,10,11,12,14,16,17

ALASKA

Alaska Services For Enabling Technology
PO Box 6485
Sitka, AK 99835
(907) 747-3019
AppleLink: ASET.SE
1,4,8,16

ARKANSAS

Technology Resource Center
c/o Arkansas Easter Seal Society
2801 Lee Ave
Little Rock, AR 72205
(501) 663-8331
(501) 660-1057 (FAX)
AppleLink: TRC
1,2,3,4,5,6,7,8,10,11,12,13,14,15,16, 17, team evaluations for augmentative communication, computer access, environmental controls, augmentative communication camp

Key

1 Hands-on computer demonstrations
2 Guided exploration and technical consultations
3 Technical assistance to employers
4 Equipment, software and video loans
5 Family support and advocacy
6 Computer camps
7 After-school programs
8 Public events and presentations
9 Minority and low-income outreach
10 Adapted toy programs
11 Toy library
12 Workshops
13 User groups
14 Early intervention services
15 Transition training for young adults
16 Technical support services
17 Professional development

CALIFORNIA

Computer Access Center
1807 Wilshire Blvd, #202
Santa Monica, CA 90403
(310) 829-6395
AppleLink: CAC.SM
1,2,3,4,5,7,8,9,12,13,14,15,16,17

DCCG—Technology Resources For People with Disabilities
2547 8th St, 12-A
Berkeley, CA 94710-2572
(510) 841-3224
(510) 841-7956 (FAX)
AppleLink: DCCG
1,2,3,4,5,6,7,8,9,10,11,12,14,16,17, works with local school districts regarding individual students on contractual basis

Foundation for Technology Access
1128 Solano Ave
Albany, CA 94706
(510) 528-0747
(510) 528-0746 (FAX)
AppleLink: FTA
3,8,9,12,11,15,16,17, national general information center

Sacramento Center for Assistive Technology
Mather Hgts Elementary School
Mather Air Force Base
Rancho Cordova, CA 95655-3399
(916) 361-0553
(916) 399-5366 (FAX)
AppleLink: SCAT
1,2,3,4,5,6,8,9,10,11,12,13,14,15, 16,17

Special Awareness Computer Center
Rehabilitation Unit North
2975 N Sycamore Dr
Simi Valley, CA 93065
(805) 582-1881
AppleLink: SACC
1,2,3,4,5,7,8,9,12,14,16,17

Special Technology Center
590 Castro St
Mountain View, CA 94041
(415) 961-6789
(415) 961-6775 (FAX)
1,2,3,5,8,9,12,14,16,17

Team of Advocates for Special Kids
100 W Cerritos
Anaheim, CA 92805-6546
(714) 533-8275
(714) 533-2533 (FAX)
AppleLink: TASK
1,2,3,4,5,7,8,9,10,11,12,14,15,16,17

FLORIDA

Computer CITE
215 E New Hampshire St
Orlando, FL 32804
(407) 898-2483
(407) 895-5255 (FAX)
AppleLink: CITE
1,2,3,4,5,6,7,8,9,10,11,12,13,14, 15,16,17

GEORGIA

Tech-Able
1040 Irwin Bridge Rd
Conyers, GA 30207-4323
(404) 922-6768
(404) 922-9813 (FAX)
AppleLink: TECHABLE
1,2,3,4,5,6,8,9,10,11,12,13,14,16, 17, Braille printer and scanner available

Alliance for Technology Access Centers

HAWAII

Aloha Special Technology Access Center
1750 Kalakaua Ave, #1008
Honolulu, HI 96826-3725
(808) 955-4464 (Voice/Fax)
AppleLink: ALOHASTAC
1,2,3,4,5,8,9,10,12,14,16

ILLINOIS

Northern Illinois Center for Adaptive Technology
3615 Louisiana Rd
Rockford, IL 61108-6195
(815) 229-2163
(815) 229-2120 (FAX)
AppleLink: ILCAT
1,2,3,4,5,8,9,12,13,14,15,16,17, information and referral for nine northern Illinois counties

Technical Aids & Assistance for the Disabled Center
1950 W Roosevelt
Chicago, IL 60608
(312) 421-3373
(312) 421-3464 (FAX)
AppleLink: TAAD
1,2,3,4,5,7,8,9,12,13,14,15,16,17

INDIANA

Assistive Technology Training and Information Center
3354 Pine Hill Dr
PO Box 2441
Vincennes, IN 47591
(812) 886-0575
(812) 882-3575 (FAX)
AppleLink: ATTIC
1,2,3,5,8,9,10,11,12,13,14,15,16, rural outreach center for training parents on federal and state education laws, curriculum adoption, inclusion

Key

1 Hands-on computer demonstrations
2 Guided exploration and technical consultations
3 Technical assistance to employers
4 Equipment, software and video loans
5 Family support and advocacy
6 Computer camps
7 After-school programs
8 Public events and presentations
9 Minority and low-income outreach
10 Adapted toy programs
11 Toy library
12 Workshops
13 User groups
14 Early intervention services
15 Transition training for young adults
16 Technical support services
17 Professional development

KANSAS

Technology Resources and Solutions for People
3023 Canterbury
Salina, KS 67401
(913) 827-0301
(913) 827-5446 (FAX)
AppleLink: TRSP
1,2,3,4,5,7,8,10,11,12,14,16

KENTUCKY

Blue Grass Technology Center for People with Disabilities
169 N Limestone
Lexington, KY 40507
(606) 255-9951
(606) 255-0059 (FAX)
AppleLink: BLUEGRASS
1,2,3,4,5,8,10,11,12,14,16,17, "Agribility" program provides technology to farmers and farm families

Disabled Citizens Computer Center
Louisville Free Public Library
301 York St
Louisville, KY 40203-2257
(502) 574-1637
(502) 574-1671 (FAX)
AppleLink: DCCC
1,2,3,5,8,9,10,11,12,14,15,16,17

FTA-Eastern Support Center
1531 Dawn Dr
Louisville, KY 40216-1617
(502) 449-0645 (Voice/Fax)
AppleLink: GLASS
East coast technical assistance office for people who want to start ATA centers in their communites

SpeciaLink
36 W 5th St
Covington, KY 41011
(606) 491-2464
(606) 491-2495 (FAX/TDD)
AppleLink: SPECIALINK
1,2,3,4,5,8,9,10,11,12,13,14,16,17

LOUISIANA

CATER-Center for Adaptive Technology and Educational Resources
4323 Division St, Ste 110-B
Metairie, LA 70002-3179
(504) 888-5248/0163
(504) 286-5588 (FAX)
AppleLink: CATER
1,2,4,5,7,8,9,10,12,15,16,17

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338-2067
(207) 582-2504
(207) 582-3638 (FAX)
AppleLink: MPF
5,9,12,16

MARYLAND

Learning Independence Through Computers
28 E Ostend St, Ste 140
Baltimore, MD 21230
(410) 659-5462
(410) 539-2087 (FAX)
AppleLink: LINC
1,2,3,4,5,6,8,9,10,12,14,16,17

MASSACHUSETTS

Massachusetts Special Technology Access Center
12 Mudge Way, 1-6
Bedford, MA 01730-2138
(617) 275-2446
AppleLink: MASTAC
1,2,3,5,6,8,10,11,12,13,16,17, software lending library, classes, referral services, newsletter

MICHIGAN

Living & Learning Resource Centre
Physically Impaired Assn of Michigan
601 W Maple St
Lansing, MI 48906-5038
(800) 833-1996 (MI)
(517) 487-0883
(517) 371-5898 (FAX)
AppleLink: LLRCPIAM
1,2,3,4,8,9,12,14,16,17

MINNESOTA

PACER Center
4826 Chicago Ave S
Minneapolis, MN 55417-1055
(612) 827-2966 (Voice/TDD)
612) 827-3065 (FAX)
AppleLink: PACER.CTR
1,2,3,4,5,8,9,10,12,13,14,15,16,17

MISSOURI

Technology Access Center
12110 Clayton Rd
St Louis, MO 63131-2599
(800) 735-2466
(314) 569-8404/8100
(314) 993-5937
(314) 569-8400 (TDD)
AppleLink: TACSTL
1,2,3,4,5,6,8,12,15,16,17

MONTANA

Parents, Let's Unite for Kids
1500 N 30th St
Billings, MT 59101-0298
(406) 657-2055
(406) 657-2061 (FAX)
AppleLink: PLUK
1,2,3,4,5,7,8,9,10,12,13,14,15,16,17, IEP support

NEW JERSEY

Computer Center for People with disAbilities
c/o Family Resource Associates
35 Haddon Ave
Shrewsbury, NJ 07702-4007
(908) 747-5310
(908) 747-5936 (FAX)
AppleLink: CCDA
1,2,5,7,8,9,10,11,12,14,16,17, Saturday pre-vocational program for teenagers

The Center for Enabling Technology
9 Whippany Rd
PO Box 272
Whippany, NJ 07981-0272
(201) 428-1455
AppleLink: CET
1,2,5,8,9,12,13,15,16,17

NEW YORK

Techspress
Resource Center for Independent Living
409 Columbia St
Utica, NY 13502
(315) 797-4642 (Voice/TDD)
(315) 797-4747 (FAX)
AppleLink: TECHSPRESS
1,2,3,4,5,7,8,9,10,11,12,13,14,15, 16,17, early intervention transition

NORTH CAROLINA

Carolina Computer Access Center
Metro School
700 E Second St
Charlotte, NC 28202-2880
(704) 342-3004 (Voice/FAX)
AppleLink: CCAC
1,2,3,4,5,6,8,9,12,14,16,17

NORTH DAKOTA

Pathfinder Parent Training and Information Center
ATA Computer Resource Center
1600 2nd Ave SW
Minot, ND 58701
(701) 852-9426/9436
(701) 838-9324 (FAX)
AppleLink: PATHFINDER
1,2,4,5,7,8,14,15,17

OHIO

Technology Resource Center
Enabling People with Disabilities
301 Valley St
Dayton, OH 45404-1840
(513) 222-5222
(513) 222-2101 (FAX)
AppleLink: TRCD
1,2,3,4,5,6,8,9,10,11,12,13,14,15, 16,17

OREGON

Oregon Outback Technology Access Center
PO Box 2916
La Grande, OR 97850
(503) 962-7258
AppleLink: OUTBACK
1,2,4,5,8,10,11,12,14,15,16

RHODE ISLAND

TechACCESS of Rhode Island
300 Richmond St
Providence, RI 02903-4222
(401) 273-1990
(401) 273-1991 (TDD)
(401) 831-1131 (FAX)
AppleLink: RHODE.ISLAND
1,2,5,8,9,12,15,16,17, Federal Technology Act Center for Rhode Island

TENNESSEE

East Tennessee Special Technology Access Center
3525 Emory Rd NW
Powell, TN 37849
(615) 947-2191
(615) 947-2194 (FAX)
AppleLink: EASTTN
1,2,3,4,5,6,7,8,9,10,11,12,13,14, 15,16,17

Technology Access Center of Middle Tennessee
Fountain Square, Ste 126
2222 Metro Center Blvd
Nashville, TN 37228
(800) 368-4651
(615) 248-6733
(615) 259-2536 (FAX)
AppleLink: TAC
1,2,3,4,5,8,9,12,14,15,16,17

West Tennessee Special Technology Resource Center
Lambuth University
Carney Johnston Hall
401 Maple St, PO Box 3683
Jackson, TN 38303-3683
(901) 424-9089
(901) 424-9090 (FAX)
AppleLink: WESTTN
1,2,3,4,5,8,9,10,11,12,13,14,15, 16,17

TEXAS

SHIP Resource Center
Univ United Methodist Church
5084 DeZavala Rd
San Antonio, TX 78249
(210) 822-0995
(210) 696-7723 (FAX)
AppleLink: SHIP
1,2,3,4,5,7,8,9,10,11,12,13,14,15, 16,17

UTAH

Computer Center for Citizens with Disabilities
c/o Horizon Elementary School
5180 S 700 W, Rm 22
Murray, UT 84123
(801) 266-0660
(801) 266-0669 (FAX)
AppleLink: CCCD
1,2,4,8,12,14,17, serves statewide augmentative communication evaluation teams

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled
PO Box 1825
St Thomas, VI 00803
(809) 777-2253
(809) 774-5816 (FAX)
AppleLink: VIRGIN.ISLDS
1,5,7,15,16

VIRGINIA

Tidewater Center for Technology Access
Special Education Annex
273 N Witchduck Rd
Virginia Beach, VA 23462-6507
(804) 473-5136
(804) 473-5659 (FAX)
AppleLink: TCTA
1,2,3,4,5,8,9,10,11,12,14,15,16,17

WASHINGTON

Washington Technology Access Center
8705 232nd Pl SW
Edmonds, WA 98026
(206) 637-9848
(206) 776-3663 (FAX)
AppleLink: WTA
Internet:
WTA@AppleLink.Apple.COM
1,2,3,4,5,7,8,9,10,11,12,13,14,15, 16,17, international newspaper; license agreements with corporations and schools; two international conferences: Pacific Northwest Technological Conference for Special Needs, Virtual Reality/Virtual Freedom conference, consults to corporations and school districts

Confidence, Independence, Success...

The Crotched Mountain Rehabilitation Center and School offers innovative academic, therapeutic, residential, and medical services designed to maximize the educational potential of physically and developmentally challenged children and young adults with:

• Head Injury • Cerebral Palsy • Spina Bifida
• Autism • Down's Syndrome • Developmental, Behavioral, Emotional and Neurological Disorders
• Fetal Substance Exposure

The CMRC program includes:

• Fully Accredited Preparatory School Curriculum
• Modern Residential Group Homes
• Licensed Nursing Facility • Day Students
• Total Communications Center
• Fully Adaptive and Accessible Sports Facility

CROTCHED MOUNTAIN
REHABILITATION CENTER INC

A subsidiary of the Crotched Mountain Foundation
1 Verney Drive Greenfield, New Hampshire 03047 (603) 547-3311

Circle #17

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle #75

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages, Inc.

A Model, Supportive Community For Mentally Retarded Adults

664EP School Street, Pembroke, MA 02359 (617) 293-5461

Circle #55

Exceptional Schools

Braintree St. Coletta Day School
Cardinal Cushing School and Training Center

Anyone who has ever visited the Cardinal Cushing School and Training Center and Braintree St. Coletta Day School will no doubt express that the experience was inspirational. The two programs, operated by St. Coletta's of Massachusetts, are reminders that miracles can happen when exceptional children are not treated as mentally disabled.

Established in 1947, St. Coletta's has blossomed into two distinct schools with over 200 staff members. The philosophy of the organization is to provide an environment where developmentally-delayed children can develop their abilities in an atmosphere of confidence and joy. Today, the schools offer what may be the best educational programs available to exceptional children, consistently producing amazing results.

At the Braintree St. Coletta Day School, approximately 70 students ages 5-22, enjoy a staff ratio of 1-3 which enables instructors to provide a high degree of personal interaction. From occupational education and behavioral management - to the development of social and domestic skills - activities enable students to gain the highest possible degree of independence. A residential component is also available.

St. Coletta's
OF MASSACHUSETTS

John W. Shyne, Jr, *President*
(617) 826-6371
Hanover, MA

Circle #73

Located in Hanover, the Cardinal Cushing School and Training Center provides roughly 160 students with academic, vocational, and residential programs for all levels of developmentally-delayed children and young adults ages 6-22. With residential placement for 130 students - accommodating 30 day attendees - the programs guide students to a chosen career by instilling in them the academic, functional and social skills.

From culinary arts and hotel maintenance, horticulture, maintenance and more, students receive hands-on training. In addition, programs in theater and sporting, as well as the benefits of living alongside peers, further increase social development. After leaving the school, most students are able to find employment. In fact, a notable alumni is Chris Burke, star of the ABC TV series "Life Goes On," introduced to performing arts through the school.

• • *Services Include* • •
Prader-Willi Program
Vocational Training
Independent Living Training
Adaptive Physical Therapy
Speech Therapy • Counseling
Community Skills • Summer Programs
Bi-Lingual (Spanish) Program

Berkshire Meadows - a place of "small miracles"

Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.

Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching,round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows,
249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

Circle #6

Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

Circle #77 *John P. Stewart, M.D., Resident Physician*

Our software can help your special child!

Laureate's award-winning software is designed by clinical experts to meet the unique needs of special infants and children. Our FREE book, *Sequential Software for Language Intervention*, tells how Laureate's talking programs can help your child build critical language and cognitive skills.

Call today for your FREE copy of *Sequential Software for Language Intervention.*

Call for a FREE catalog, book, and video.
1-800-562-6801
Circle #48

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Colleta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills, personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

In A World Where Love Is Sometimes In Short Supply

We Have It In Abundance

NINETY YEARS

St. Coletta School

W4955 Highway 18
Jefferson, Wisconsin 53549

Circle #74

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.

State Assistive Technology Programs

The following programs are administered by the National Institute on Disability and Rehabilitation Research. They offer a wide range of information on assistive technology devices and services. This list was provided by the RESNA Technical Assistance Project, a federally funded project which provides consultation and information to state programs and the general public. For more information, contact the RESNA Technical Assistance Project, 1700 Connecticut Avenue, NW, Washington, DC 20036, (202) 857-1140.

ALABAMA

Alabama Department of Education
Division of Rehabilitation Services
2129 East South Blvd
Montgomery, AL 36111
(205) 281-8780

ALASKA

Assistive Technologies of Alaska
400 D St, Ste 230
Anchorage, AK 99501
(907) 274-0138 (Voice/TDD)
(800) 770-0138 (Voice/TDD)
(907) 274-1399 (FAX)

ARKANSAS

Arkansas Increasing Capabilties Access Network
2201 Brookwood, Ste 117
Little Rock, AR 72202
(501) 666-8868 (Voice/TDD)
(800) 828-2799 (In-state only)
(501) 666-5319 (FAX)

CALIFORNIA

Independent Living Division
California Dept of Rehabilitation
830 K St Mall, 2nd Fl
Sacramento, CA 95814
(916) 323-0595

COLORADO

Colorado Assistive Technology Project
Rocky Mountain Resource and Training Institute
6355 Ward Rd, Ste 310
Arvada, CO 80004
(303) 420-2942 (Voice/TDD)
(303) 420-8675 (FAX)

CONNECTICUT

Connecticut Assistive Technology Project
Bureau of Rehabilitation Services
10 Griffin Rd N
Windsor, CT 06095
(203) 298-2042
(203) 298-9590 (FAX)

DELAWARE

Delaware Assistive Technology Initiative
Applied Science and Engineering Laboratories
University of Delaware
A.I. duPont Institute
1600 Rockland Rd, Rm 154
Wilmington, DE 19899
(302) 651-6790
(302) 651-6794 (TDD)
(302) 651-6793 (FAX)

DISTRICT OF COLUMBIA

RESNA Technical Assistance Project
1101 Connecticut Ave NW, Ste 700
Washington, DC 20036
(202) 857-1140 (Voice/TDD)
(202) 223-4579 (FAX)

DC Partnership for Assistive Technology
National Rehabilitation Hospital
102 Irving St NW
Washington, DC 20010
(202) 877-1498

FLORIDA

Florida Assistive Technology Project
Dept of Labor & Employment
Div of Vocational Rehabilitation
Bureau of Client Services
Rehabilitation Engineering Technology
1709-A Mahan Dr
Tallahassee, FL 32399-0696
(904) 488-8380
(904) 488-6210 (FAX)

GEORGIA

Georgia Tools For Life
Division of Rehabilitation Services
2 Peachtree St NW, Ste 23-411
Atlanta, GA 30303
(800) 726-9119
(404) 894-4960
(404) 657-3084
(404) 657-3085 (TDD)
(404) 657-3086 (FAX)

HAWAII

Hawaii Assistive Technology System
677 Ala Moana Blvd, Ste 403
Honolulu, HI 96813
(808) 532-7110 (Voice/TDD)
(808) 532-7120 (FAX)

IDAHO

Idaho Assistive Technology Project
129 W Third St
Moscow, ID 83843
(208) 885-9429
(208) 885-6849
(208) 885-9056 (FAX)

ILLINOIS

Illinois Assistive Technology Project
110 ILES Park Pl
Springfield, IL 62718
(800) 852-5110 (In state only—Voice/TDD)
(217) 522-7985 (Voice/TDD)
(217) 522-8067 (FAX)

INDIANA

Indiana Attain (Accessing Technology Through Awareness in Indiana) Project
Indiana Family and Social Services Admin
Division of Aging and Rehabilitation Services
402 W Washington St, Rm W453
PO Box 7083
Indianapolis, IN 46207-7083
(800) 545-7763
(812) 855-9396
(812) 855-9630 (FAX)

IOWA

Iowa Program For Assistive Technology
Iowa Univ Affiliated Program
Univ Hospital School
Iowa City, IA 52242
(800) 331-3027
(319) 353-6386
(319) 356-8284 (FAX)

State Assistive Technology Programs

State Assistive Technology Programs

KANSAS

Life Span Institute
Univ of Kansas
PO Box 738
Parsons, KS 67357
(316) 421-6550 Ext 1890/1854

KENTUCKY

Kentucky Assistive Technology Services Network
Coordinating Center
427 Versailles Rd
Frankfort, KY 40601
(502) 564-4665 (Voice/TDD)
(502) 564-3976 (FAX)

LOUISIANA

Louisiana Technology Assistance Network
PO Box 3455, Bin #14
Baton Rouge, LA 70821-3455
(800) 922-3425
(800) 256-1633 (TDD)
(504) 342-2471 (Voice/TDD)
(504) 342-4419 (FAX)

MAINE

Maine Consumer Information and Technology
Training Exchange (Maine CITE)
Maine CITE Coordinating Center
Univ of Maine at Augusta
University Heights
Augusta, ME 04330
(207) 621-3195 (Voice/TDD)
(207) 621-3193 (FAX)

MARYLAND

Maryland Technology Assistance Program
Governor's Office for Handicapped Individuals
300 W Lexington St, Box 10
Baltimore, MD 21201
(800) 838-4827
(410) 333-4975
(410) 333-6674 (FAX)

MASSACHUSETTS

Massachusetts Assistive Technology Partnership Ctr
Children's Hospital
300 Longwood Ave
Boston, MA 02115
(617) 727-5540
(617) 345-9743 (TDD)
(617) 735-7820
(617) 735-6345 (TDD)
(617) 735-6345 (FAX)

MICHIGAN

Michigan Assistive Technology Project
Michigan Dept of Education
Rehabilitation Services
PO Box 30010
Lansing, MI 48909
(517) 373-4056
(517) 373-4058 (FAX)

MINNESOTA

Minnesota Star Program
300 Centennial Bldg
658 Cedar St
St. Paul, MN 55155
(800) 331-3027
(612) 297-1554
(612) 296-9962 (TDD)
(612) 297-7200 (FAX)

MISSISSIPPI

Mississippi Project Start
PO Box 1698
300 Capers Ave, Bldg 3
Jackson, MS 39215-1698
(601) 354-6891 (Voice/TDD)
(601) 354-6080 (FAX)

MISSOURI

Missouri Assistive Technology Project
Univ of Missouri-Kansas City
Rm 117 EDUC
5100 Rockhill Rd
Kansas City, MO 64110-2499
(816) 235-5342
(816) 235-5339
(800) 647-8558 (TDD)
(816) 235-5270 (FAX)

MONTANA

MonTECH
The Univ of Montana
MUARID, MonTECH
634 Eddy Ave
Missoula, MT 59812
(406) 243-5676
(406) 243-2349 (FAX)

NEBRASKA

Nebraska Assistive Technology Project
301 Centennial Mall S
PO Box 94987
Lincoln, NE 68509-4987
(402) 471-0734
(402) 471-3647 (Voice/TDD)
(402) 471-0117 (FAX)

NEVADA

Nevada Assistive Technology Project
Rehabilitation Division
Community-Based Services Dept
711 S Stewart St
Carson City, NV 89710
(702) 687-4452
(702) 687-3388 (TDD)
(702) 687-3292 (FAX)

NEW HAMPSHIRE

New Hampshire Technology Partnership Project
Institute on Disability
Ten Ferry St, #14
The Concord Center
Concord, NH 03301
(603) 224-0630 (Voice/TDD)
(603) 228-3270 (FAX)

NEW JERSEY

New Jersey Technology Assistive Resource Program
Labor Building, Room 806, CN 938
Trenton, NJ 08625
(609) 292-7496
(609) 292-7556
(609) 292-4616 (FAX)

NEW MEXICO

New Mexico Technology Assistance Program
435 St. Michael's Dr, Bldg D
Santa Fe, NM 87503
(800) 866-2253 (Voice/TDD)
(505) 827-3532 (Voice/TDD)
(505) 827-3746 (FAX)

NEW YORK

New York State Triad Project
Office of Advocate for the Disabled
One Empire State Plaza, Tenth Fl
Albany, NY 12223-0001
(518) 474-2825
(518) 473-4231 (TDD)
(518) 473-6005 (FAX)

NORTH CAROLINA

North Carolina Assistive Technology Project
Dept of Human Resources
Division of Vocational Rehabilitation Services
1110 Navaho Dr, Ste 101
Raleigh, NC 27609
(800) 852-0042
(919) 850-2787 (Voice/TDD)
(919) 850-2792 (FAX)

NORTH DAKOTA

Director of Rehabilitation
Office of Rehabilitation
400 E Broadway, Ste 303
Bismarck, ND 58501
(701) 224-3999

OHIO

Ohio Assistive Technology Project
400 E Campus View Blvd, SW5F
Columbus, OH 43235-4604
(614) 438-1450
(614) 438-1257 (FAX)

OKLAHOMA

Oklahoma Assistive Technology Project
Dept of Human Services
Rehabilitation Services Division
DHS, RS #24
PO Box 25352
Oklahoma City, OK 73125
(405) 424-4311
(405) 427-2753 (FAX)

OREGON

Oregon Technology Access For Life Needs Project
Chemeketa Community College
TALN Center
4000 Lancaster Dr, NE
Bldg 5, Rm 103
PO Box 14007
Salem, OR 97309-7070
(503) 399-6977
(503) 378-2756 (FAX)

PENNSYLVANIA

Pennsylvania's Initiative on Assistive Technology
Institute on Disability/UAP
Ritter Hall Annex 433 (004-00)
Philadelphia, PA 19122
(215) 204-1356
(800) 204-7428 (Voice/TDD)
(215) 204-6336 (FAX)

PUERTO RICO

Project Director
Box 22484
University of Puerto Rico Station
Rio Piedras, PR 00931
(809) 754-8926

RHODE ISLAND

Office of Rehabilitation Services
40 Fountain St
Providence, RI 02903
(401) 421-7005

SAMOA

American Samoa Division of Vocational Rehabilitation
Dept of Human Resources
Pago Pago, American Samoa
96799
(684) 633-2336
(684) 633-7183

SOUTH CAROLINA

South Carolina Assistive Technology Program
Vocational Rehabilitation Dept
PO Box 15
1410-C Boston Ave
West Columbia, SC 29171-0015
(803) 822-5404 (Voice/TDD)
(803) 822-4301 (FAX)

SOUTH DAKOTA

Dakota Link
1925 Plaza Blvd
Rapid City, SD 57702
(800) 645-0673 (Voice/TDD)
(605) 394-1876
(605) 394-5315 (FAX)

TENNESSEE

Tennessee Technology Access Project
Office of Assistive Technology—Central Office
Doctor's Bldg, Ste 300
706 Church St.
Nashville, TN 37243-0675
(800) 732-5059 (in TN)
(615) 741-7441
(615) 741-0770 (FAX)

TEXAS

Texas Assistive Technology Project
The University of Texas at Austin
UAP of Texas
Dept of Special Education, EDB 306
Austin, TX 78712
(512) 471-7621

UTAH

Utah Assistive Technology Program
Ctr for Persons with Disabilities
UMC 6855
Logan, UT 84322
(800) 333-8824
(801) 750-1982
(801) 750-2355 (FAX)

VERMONT

Vermont Assistive Technology Project
103 S Main St, Weeks I
Waterbury, VT 05671-2305
(802) 241-2620 (Voice/TDD)
(802) 241-3052 (FAX)

VIRGINIA

Virginia Assistive Technology System
4900 Fitzhugh Ave
Richmond, VA 23230
(804) 367-2442
(804) 367-2445 (Voice/TDD)
(804) 367-2440 (FAX)

WASHINGTON

DSHS/DVR
PO Box 45340
Olympia, WA 98504-5340
(206) 438-8049

WEST VIRGINIA

West Virginia Assistive Technology System
Division of Rehabilitation Services
Capital Complex
Charleston, WV 25305-0890
(800) 841-8436
(304) 766-4698
(304) 293-7294 (FAX)

WISCONSIN

Division of Vocational Rehabilitation
PO Box 7852
1 W Wilson St, Rm 950
Madison, WI 53707-7852
(608) 266-5395
(608) 267-6720
(608) 266-9599 (TDD)

WYOMING

Program Consultant
Div of Vocational Rehabilitation
1100 Herschler Bldg
Cheyenne, WY 82002
(307) 777-6841

THE DUVALL HOME, EST. 1945. A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:

- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874
(800) 358-0450

STROLL INTO A NEW WORLD

Not only can you take your child to places you both would like to go, our **SPECIAL NEEDS STROLLER PACK** will give your child a whole new outlook.

STROLLER Pack
A Way of Life

Call for Information
1-800-487-9652

Circle #78
SKAGGS & INGALLS INC

REACH FOR THE STARS... STEP UP IN STYLE!

Now, from the ***convenience of home,*** shop from **The Starlight Collection Catalog** and discover a spectacular selection of easy-on, easy-off footwear. From sport shoes to dress shoes, each pair is sure to have just the features you're looking for...

- ★ Super styles
- ★ Lasting comfort
- ★ Extra support
- ★ Easy-on, Easy-off
- ★ Narrow, Medium, Wide Widths
- ★ Many styles machine-washable
- ★ Great shoes for men, women and children!

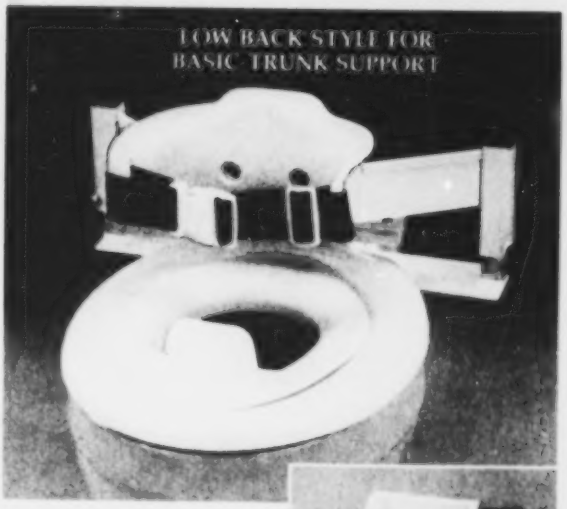
THE PUMA DISC—Just one of **Starlight's** great shoes that are truly "easy to wear."

Here's a sensational shoe that's incredibly easy to slip on and off. A simple twist tightens it up, a gentle push of the button slips it off. No more tie-ups with hard to manage laces!

See for yourself just how easy ***and fun*** a new pair of shoes can be!
Call today for your **FREE Starlight Collection** Catalog
1-800-55-SHOES Circle #76
Starlight Footwear ★ 21537 Kapok Circle ★ Boca Raton, FL 33433

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support



The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

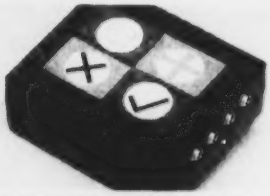
Handsome, durable and convenient to use!

Contact us for your nearest dealer

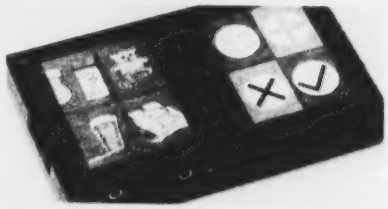
COLUMBIA

Carry your voice in *STYLE* with the Voicemate Series from TASH

Communication doesn't get any easier.



2703 Switchmate 4 Direct Select plus Direct Single Switch Access



2708 Scanmate 8 Direct Select plus Automatic or Step Scanning

Now you can say what you want to say *wherever you go* – with TASH's portable communication aids. There's *no* simpler way to record and play your messages – and their *sound* quality is *unbeatable!!*

Circle #101

tash INC.

Phone or fax us for more details!
Technical Aids & Systems for the Handicapped Inc.
Unit 1 – 91 Station Street, Ajax, ON, Canada L1S 3H2
Phone (905) 686-4129 • Fax (905) 686-6895

AlphaTalker™

A New Dimension In Communication

AlphaTalker is a simple, lightweight communication device that is anything but basic. Its sleek, durable case houses more capabilities than any other device in its class. Designed for people with limited communication needs, it can also be used as an introductory device, as an evaluation tool, or for someone with a short-term speech loss. For further information, call us.

Prentke Romich Company
1022 Heyl Rd. Wooster, OH 44691
800-262-1984 • 216-262-1984

Circle #61

Working together for a better future!

At Devereux, the concept of working together is emphasized and encouraged.

In residential, day, and community-based treatment centers nationwide, Devereux provides comprehensive services to individuals of all ages who have:

- Emotional disturbances
- Developmental disabilities
- Mental retardation
- Dual diagnoses
- Autism
- Post-head trauma

Devereux services:

- A wide range of therapeutic, educational, and vocational programs tailored to the specific needs of the individual
- Individual, group, and family therapies

Devereux programs:

- Residential centers
- Specialized psychiatric hospitals/intensive residential treatment centers
- Community-based living

Devereux locations:
Arizona, California, Connecticut, Delaware, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Texas.

Contact: National Referral Services
1-800-345-1292, X3045 or
215/964-3045
FAX: 215/971-4600

The Devereux Foundation

CHARLES C THOMAS • PUBLISHER

☐ Camerer, M. C. Gore—**A PARENT'S GUIDE TO COPING WITH ADOLESCENT FRIENDSHIPS: The Three Musketeer Phenomenon.** '94, 186 pp. (7 × 10), 1 il.

☐ Giordano, Gerald—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $36.75.

☐ Kass, Corrine E. & Cleborne D. Maddux—**A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice.** '93, 222 pp. (7 × 10), 3 il., $45.75.

☐ Kluwin, Thomas N. & Michael S. Stinson—**DEAF STUDENTS IN LOCAL PUBLIC HIGH SCHOOLS: Backgrounds, Experiences, and Outcomes.** '93, 174 pp. (7 × 10), 30 il., 10 tables, $38.75.

☐ Koziol, Leonard F., Chris E. Stout & Douglas H. Ruben—**HANDBOOK OF CHILDHOOD IMPULSE DISORDERS AND ADHD: Theory and Practice.** '93, 252 pp. (7 × 10), 2 il., 18 tables, $53.75.

☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.

☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¾ × 9¼), 113 il., 19 tables, $59.75.

☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 x 10), 21 il., $37.75.

☐ Schwenn, John O., Anthony F. Rotatori and Robert A. Fox—**UNDERSTANDING STUDENTS WITH HIGH INCIDENCE EXCEPTIONALITIES: Categorical and Noncategorical Perspectives.** '91, 272 pp. (7 × 10), 4 il., 15 tables, $43.75.

☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), $35.75.

☐ Thompson, Richard H. & Gene Stanford—**CHILD LIFE IN HOSPITALS: Theory and Practice.** '81, 286 pp., 1 table, $36.50, spiral (paper).

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 314 pp. (6¼ × 9¼), 100 il., 14 tables.

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.

☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.

☐ Rakow, Sue F. V. & Carol B. Carpenter—**SIGNS OF SHARING: An Elementary Sign Language and Sex Awareness Curriculum.** '93, 380 pp. (8½ × 11), 245 il., $45.75.

☐ Adamo-Tumminelli, Pat—**A GUIDE TO PEDIATRIC TRACHEOTOMY CARE. (2nd Ed.)** '93, 114 pp. (8½ × 11), 46 il., spiral (paper).

☐ King, Margaret A., Anne E. Oberlin and Terry Swank—**CREATING A CHILD-CENTERED DAY CARE ENVIRONMENT FOR TWO-YEAR-OLDS.** '93, 144 pp. (7 × 10), $32.75.

☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 × 10), $47.75.

☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $50.50.

☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.

☐ Irons-Reavis, Donna—**EDUCATIONAL INTERVENTION FOR THE STUDENT WITH MULTIPLE DISABILITIES.** '92, 140 pp. (7 × 10), 31 il., $30.75.

☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, $52.75.

☐ Hughes, Barry K.—**PARENTING A CHILD WITH TRAUMATIC BRAIN INJURY.** '90, 111 pp. (7 × 10), 3 il., $28.50.

☐ Hulit, Lloyd M.—**STUTTERING THERAPY: A Guide to the Charles Van Riper Approach.** '85, 92 pp., $22.00.

Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice

Circle #10

2600 South First Street Springfield • Illinois • 62794-9265

Federal Agencies

National Division of *Birth Defects and Developmental Disabilities*
Center for Environmental Health
Centers for Disease Control
4770 Buford Hwy NE
Mailstop F-45
Atlanta, GA 30341-3724
(404) 488-7160
(404) 488-7197 (FAX)

National Library Service for the *Blind and Physically Handicapped* (NLS)
Library of Congress
1291 Taylor St NW
Washington, DC 20542
(800) 424-8567
(202) 707-5100
(202) 707-0744 (TDD)
(202) 707-0712 (FAX)

National Institute of *Child Health and Human Development* (NICHD)
National Institutes of Health
US Dept of Health and Human Services
9000 Rockville Pike
Bldg 31, Rm 2A32
Bethesda, MD 20892
(301) 496-5133
(301) 496-7101 (FAX)

***Deafness and Communicative Disorders* Branch**
Rehabilitation Services Administration
US Dept of Education
Switzer Bldg
330 C St SW
Washington, DC 20202
(202) 205-9698
(202) 205-8919 (TDD)
(202) 205-9772 (FAX)

Administration on *Developmental Disabilities* (ADD)
Office of Human Development Services
US Dept of Health and Human Services
HHH Bldg, Rm 329D
200 Independence Ave, SW
Washington, DC 20201
(202) 690-6590

Senate Subcommittee on *Disability Policy*
113 Hart Senate Office Bldg
Washington, DC 20510
(202) 224-6265
(202) 224-3457 (TDD)
(202) 228-2923 (FAX)

President's Committee on *Employment of People with Disabilities*
1331 F St NW, 3rd Fl
Washington, DC 20004
(202) 376-6200
(202) 376-6205 (TDD)
(202) 376-6219 (FAX)

Office of *Fair Housing and Equal Opportunity*
Dept of Housing and Urban Development
820 1st St NE, Ste 450
Washington, DC 20002
(202) 275-0848
(202) 275-0772 (TDD)
(202) 275-0779 (FAX)

Project *Head Start*
Head Start Bureau
Administration for Children, Youth and Families
US Dept of Health and Human Services
Switzer Bldg
330 C St SW
Washington, DC 20201
(202) 205-8578
(202) 401-5916 (FAX)

***Maternal and Child Health* Bureau**
Health Resources & Services Administration
5600 Fishers Ln, Rm 905
Rockville, MD 20857
(301) 443-2350
(301) 443-1728 (FAX)

President's Committee on *Mental Retardation*
Wilbur J. Cohen Bldg, Rm 5325
330 Independence Ave SW
Washington, DC 20201
(202) 619-0634
(202) 205-9519 (FAX)

Federal agencies can provide information on programs, services and related laws and regulations.

National Institute of *Neurological Disorders and Stroke*
National Institutes of Health
US Dept of Health and Human Services
9000 Rockville Pike
Bldg 31, Rm 8A-16
Bethesda, MD 20892
(800) 352-9424
(301) 496-5751

***Social Security* Administration**
6401 Security Blvd
Baltimore, MD 21235
(800) 772-1213 (Voice Hotline)
(800) 325-0778 (TDD Hotline)
(410) 965-7700 (Voice)
(410) 965-0695 (FAX)

Office of *Special Education and Rehabilitative Services*
U.S. Office of Education
Switzer Bldg
330 C St SW
Washington, DC 20201
(202) 205-8723
(202) 205-8141, Clearinghouse (Voice/TDD)
(202) 205-9252 (FAX)

FREE SAMPLES. FREE DELIVERY. FREE CATALOG.

Baby, Youth, Adult.

Compare Our Cost & Service On:

Attends	No-Rinse Products
Dignity	Promise
Depends	Tranquility

CompCare has in inventory a full range of sizes. Fast, free delivery anywhere in continental U.S.

1-800-877-7317

CompCare Circle #14

The Leading Edge of Health Care Excellence

5534 Cortez Road West • Bradenton, FL 34210

CompCare is accredited by Joint Commission on Accreditation of Health Care Organizations.

NO ONE makes environmental control easier than TASH!

8200 Relax – Trainable Infrared Scanner

There is no simpler way to control your TV, VCR or any other infrared equipment. The Relax can learn and control the functions of up to four different infrared devices with only a single switch. It can also operate up to 10 different appliances in your house, when used with TASH's X-10 Controller plus modules.

tash INC. Circle #102

Phone or fax us for more details!

Technical Aids & Systems for the Handicapped Inc.

Unit 1, 91 Station Street, Ajax, Ontario, Canada L1S 3H2

Phone (905) 686-4129 • Fax (905) 686-6895

5 Models Available Now

The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Circle #43 **Photo used by permission Hedstrom Corp. of Bedford, PA**

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator

1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392

(609) 346-3300 • FAX (609) 435-4223

Brochure or video available upon request.

"Accreditation with Commendation" Circle #85

Joint Commission on Accreditation of Hospital Organizations

Member: National Association of Children's Hospitals and Related Institutions

Federal Health Information Centers and Clearinghouses

National *Adoption* Information Clearinghouse
11426 Rockville Pike, Ste 410
Rockville, MD 20852
(301) 231-6512
(301) 984-8527 (FAX)

Centers for Disease Control National *AIDS* Clearinghouse
PO Box 6003
Rockville, MD 20849-6003
(800) 458-5231
(800) 342-2437 (English hotline)
(800) 344-7432 (Spanish hotline)
(800) 243-7012 (TDD)
(301) 738-6616 (FAX)

National Institute of *Allergy and Infectious Diseases*
Office of Communications
Bldg 31, Rm 7A50
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5717
(301) 402-0120 (FAX)

National *Arthritis and Musculoskeletal and Skin Diseases* Information Clearinghouse
PO Box AMS
9000 Rockville Pike
Bethesda, MD 20892
(301) 495-4484
(301) 587-4352 (FAX)

***Cancer* Information Service**
National Institutes of Health
Office of Cancer Communications
Bldg 31, Rm 10A16
9000 Rockville Pike
Bethesda, MD 20892
(800) 422-6237

National Information Center for *Children and Youth With Disabilities*
PO Box 1492
Washington, DC 20013
(202) 416-0300 (Voice/TDD)
(202) 416-0312 (FAX)

National Institute on *Deafness and other Communication Disorders* Information Clearinghouse
PO Box 37777
Washington, DC 20013
(800) 241-1044 (Voice)
(800) 241-1055 (TDD)
(301) 565-4020
(301) 402-0018 (FAX)

National *Diabetes* Information Clearinghouse
PO Box NDIC
9000 Rockville Pike
Bethesda, MD 20892
(301) 468-2162
(301) 907-8906 (FAX)

National *Digestive Diseases* Information Clearinghouse
PO Box NDDIC
9000 Rockville Pike
Bethesda, MD 20892
(301) 468-6344
(301) 907-8906 (FAX)

ERIC Clearinghouse on *Disabilities and Gifted Education*
Council for Exceptional Children
1920 Association Dr
Reston, VA 22091
(800) 328-0272
(703) 620-3660 (TDD)
(703) 264-9494 (FAX)

Clearinghouse on *Disability* Information
Office of Special Education and Rehabilitative Services
Dept of Education
330 C St SW
Switzer Bldg, Rm 3132
Washington, DC 20202-2524
(202) 205-8241 (Voice/TDD)
(202) 205-9252 (FAX)

***Educational Resources* Information Center (ERIC)**
Central ERIC
U.S. Dept of Education
Washington, DC 20208
(202) 219-2289
(202) 219-1817 (FAX)

National Clearinghouse on *Family Support and Children's Mental Health*
Portland State Univ
PO Box 751
Portland, OR 97207-0751
(800) 628-1696
(503) 725-4165 (TDD)
(503) 725-4180 (FAX)

National *Health* Information Ctr
National Institutes of Health
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797

National *Heart, Lung, and Blood* Institute
Education Programs Info Ctr
PO Box 30105
Bethesda, MD 20824-0105
(301) 251-1222
(301) 251-1223 (FAX)

National Information Clearinghouse for *Infants with Disabilities and Life-threatening Conditions*
Univ of South Carolina
Benson Bldg
Columbia, SC 29208
(800) 922-9234 ext. 201
(803) 777-6058 (FAX)

National *Injury* Information Clearinghouse
4340 East-West Hwy
Washington, DC 20207
(301) 504-0424
(301) 504-0124 (FAX)

National *Kidney and Urologic Diseases* Information Clearinghouse
PO Box NKUDIC
9000 Rockville Pike
Bethesda, Md 20892
(301) 468-6345
(301) 907-8906 (FAX)

National *Maternal and Child Health* Clearinghouse
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955 ext 254, 265
(703) 821-2098 (FAX)

National Institute of *Mental Health*
5600 Fishers Ln, Rm 15C05
Rockville, MD 20857
(301) 443-4513

***Minority Health* Resource Center**
PO Box 37337
Washington, DC 20013-7337
(800) 444-6472
(301) 565-5112 (FAX)

Federal Health and Information and Clearinghouses

National Information Center for *Orphan Drugs and Rare Diseases*
Office of Orphan Products Development
PO Box 1133
Washington, DC 20013-1133
(301) 443-2043
(800) 300-7469
(301) 443-4915 (FAX)

National Clearinghouse on *Postsecondary Education for Individuals with Disabilities*
HEALTH Resource Ctr
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284
(202) 939-9320 (Voice/TDD)

National *Rehabilitation* Information Clearinghouse
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(800) 346-2742 (Voice/TDD)
(301) 588-9284 (Voice/TDD)
(301) 587-1967 (FAX)

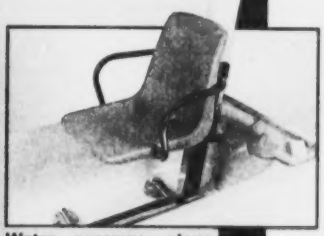
National *Sudden Infant Death Syndrome* Resource Ctr
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955
(703) 821-2098 (FAX)

National Information System for *Vietnam Veterans and Their Families*
Ctr for Developmental Disabilities
Univ of South Carolina
Benson Bldg
Columbia, SC 29208
(800) 922-9234 ext 401
(803) 777-6058 (FAX)

BATH-MATE ™

Water Powered Bath Lift

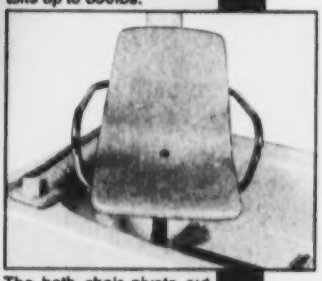
The Bath-Mate fits your existing tub without modifications



Water pressure alone supplies the lifting action. Lifts up to 350lbs.

Safe Bathing Promotes more Independence....

The Bath-Mate raises slowly to wheelchair height and lowers within 2 inches of tub bottom.



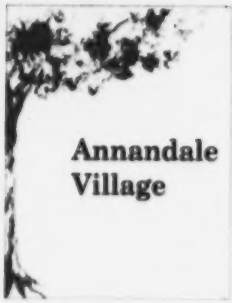
Optional:
- Seat Belts
- Arm Rest

The bath chair pivots outward for safe transfers.

(800)947-6565

P.O. Box 80095 Ontario, Ca. 91758

Circle #67



Annandale Village

"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for adults with developmental disabilities. Residential and day/evening programs and services.
- Paid Job Training
- Arts Activities.
- Therapeutic recreation.
- Case management.
- 125-acre wooded environment.

Annandale at Suwanee, Inc.
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381

"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

SHEVET ACHIM in conjunction with YACHAD/NCSY is a new & exciting summer program in an Israeli Kibbutz. This four week program is designed specifically for high functioning Jewish young adults with developmental disabilities. Located in Kibbutz Ein Zurim, central Israel. Sabbath and Kosher dietary laws observed.

SHEVET ACHIM
63-67 108th Street
Forest Hills, New York 11375
(718) 997-1111 New York
(213) 930-5122 Los Angeles
(312) 764-4019 Chicago

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 31st year. Free brochure.

33rd Year

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

1993 Exceptional Parent Topical Index

The 1993 Exceptional Parent Topical Index is organized by article title, issue and page number.

Accessibility

Accessibility Guidelines Checklist ..... Oct 58
Adventures in Camping ..... Apr/May 20
European Camping Holidays Available ..... Feb 55
Making Your Home Work—Ramps ..... Apr/May 30
Study on Bus Access Released ..... Oct 58

Americans with Disabilities Act (ADA)

ADA Guide ..... Oct 58
Project Offers Info on ADA Compliance ..... Feb 55

Adaptive Equipment

Aquatic Sports ..... Jul/Aug 30
Insurance Claim Appeal ..... Mar 30
Selecting a Seating System ..... June 42
When Your Child Goes to School After an Injury, Getting To and From School Safely ..... Mar 62/June 55
Working Toward A Balance in Our Lives ..... Mar 64

Advocacy

Effective Parent Advocacy: How to Take Charge ..... Sept 73
Family Support Action Pack ..... Oct 58
Family Support Programs Growing ..... Jul/Aug 36
No Pity ..... Oct 35
When Your Child Goes to School After an Injury, From Hospital to School ..... Apr/May 44

Assistive Technology

Best Interests of the Child, The ..... Apr/May 46
Family Hall of Fame: Jan Little ..... Mar 16
Finding Funding for Assistive Technology ..... Mar 18
Getting Started with Computers ..... Nov/Dec 27
Making Your Home Work—Ramps ..... Apr/May 30
Report on Assistive Technology ..... Nov/Dec 47
Technology Use at Home ..... Nov/Dec 36
Telecommunications ..... Nov/Dec 62
Careers and Technology Information Bank ..... Sept 92

Attention Deficit Hyperactivity Disorder

On-Line Bulletin Board for ADD ..... Sept 92
Attention Deficit Hyperactivity Disorder ..... Sept 64

Book Excerpts

Attention Deficit Hyperactivity Disorder ..... Sept 64
Helping Children Overcome Learning Difficulties ..... Oct 36
It Isn't Fair ..... Jul/Aug 56
One Miracle at a Time ..... Feb 52
Physical Activity for Individuals with Mental Retardation ..... June 58
Planning for the Future ..... Apr/May 52
No Pity ..... Oct 35
Report on Assistive Technology ..... Nov/Dec 54
When Your Child Goes to School After an Injury, From Hospital to School ..... Apr/May 44
When Your Child Goes to School After an Injury, Getting To and From School Safely ..... Mar 62/June 55
When Your Child Goes to School After an Injury, Preparation and Communication Between Families and Schools ..... Jul/Aug 53
Working Toward A Balance in Our Lives ..... Mar 64

Camping

1992 Summer Program Awards ..... Apr/May 18
1992 Summer Program Awards ..... June 24
Adventures in Camping ..... Apr/May 20
European Camping Holidays Available ..... Feb 55
EP's Guide to Summer Fun ..... Apr/May 36

Communication

Audiology/Pathology Insurance Coverage ..... June 60
Best Interests of the Child, The ..... Apr/May 46
Circle of Friends ..... Feb 24
Communication Needs in the U.S. ..... Mar 72
How Does Your Child Hear and Talk? ..... Oct 59
Newsletter Started for Parents of Children with Developing Language ..... Jul/Aug 54

Coping

Baby Girl ..... Mar 34
Finding the Fun ..... Jul/Aug 32
Fine Purpose, A ..... Oct 23
Learning to See the Bright Side ..... Jul/Aug 16
Miracles of Brea, The ..... Apr/May 22
On the Ice ..... Feb 42
One Miracle at a Time ..... Feb 52
Parent to Parent National Survey ..... Nov/Dec 42
Reaching Out ..... Jul/Aug 20
Residential Placement: Coping with Separation ..... Sept 67

Directories

Accessible Easter Seal Camps and Specialized Hospital-Affiliated Camps ..... Apr/May 38
Accessibility Offices, state-by-state list ..... Mar 38
Alliance for Technology Access Centers ..... Nov/Dec 33

1993 Exceptional Parent Topical Index

National Organizations ..... Sept D1

Special Services Offered by Major Theme Parks, National Parks and National Recreation Organizations ..... June 32

Toll-Free Information Numbers ..... Feb 44

Editorials

Being Realistic ..... Apr/May 14

Best is Yet to Come, The ..... Jul/Aug 14

Educational Excellence for All ..... Oct 53

Health Care Reform—Write Now ..... Oct 42

Investing in All Children ..... Mar 14

Letter to President Clinton ..... Feb 14

Liberty and Choices for All ..... Jun 14

Education

1993 School Inclusion Award: Des Moines ..... Sept 15

All Children Belong ..... Nov/Dec 47

Best Interests of the Child, The ..... Apr/May 46

Booklet Helps Students with Disabilities Choose a College ..... Jul/Aug 54

Circle of Friends ..... Feb 24

College Goals ..... Sept 92

Education of Students with PKU ..... Apr/May 50

Financial Aid Paper ..... Apr/May 50

Helping Children Overcome Learning Difficulties ..... Oct 36

Inclusion: An Administrator's Perspective ..... Sept 22

Inclusion: A Child's Perspective ..... Sept 17

Inclusion: A Parent's Perspective ..... Sept 18

Inclusion: Future Goals ..... Sept 25

Inclusion in Education: A Choice for Your Child ..... Nov/Dec 46

NPND Policy Statement on Education Reform ..... Mar 67

NPND Position on Inclusion ..... Nov/Dec 44

NPND Position on School Reform ..... Nov/Dec 45

Parent-Teacher Cooperation—A Shared Responsibility ..... Sept 31

Parent Leaders Develop Legislative Agenda ..... Nov/Dec 43

School Mainstreaming Contest Winners, 1992 ..... Feb 36

Tough Choice ..... Apr/May 24

Employment

Careers and Technology Information Bank ..... Sept 92

New Documentary Encourages Careers in Engineering ..... Jul/Aug 54

Service Helps Find Job Candidates with Disabilities ..... June 60

Family Life

David Should Have a Graduation Party, Too ..... June 62

Kindness ..... Oct 62

Meetings Are Always Unpleasant For Us ..... Mar 80

We Continued the School People's Fight at Home ..... Feb 48

Family support

Family Support Legislation Drafted ..... Sept 86

Family Support Programs Growing ..... Jul/Aug 36

Fathers

Images of Fathers ..... Oct 49

Kevin Christman's "Father of the Year" ..... Sept 96

Merry-Go-Round, The ..... June 20

Silent Ringmaster, The ..... Nov/Dec 40

Feeding

Evaluating Feeding Concerns ..... June 72

Financial Planning

Annual Income Tax Guide ..... Feb 38

Children May Benefit from New SSI Rule ..... Apr/May 50

Financial Aid Paper ..... Apr/May 50

Planning for the Future ..... Apr/May 52

Report on Assistive Technology ..... Nov/Dec 47/54

Tax on Customized Vehicles Repealed ..... Nov/Dec 47/54

Funding

Auto Industry Offers Incentives ..... Jul/Aug 46

Financial Aid Paper ..... Apr/May 50

Finding Funding for Assistive Technology ..... Mar 18

Genetics

Scientists Isolate Gene Believed to Cause ALD ..... Apr/May 50

Government Agencies

Bob Williams Appointed DD Commissioner ..... Sept 84

Disability advocate to head OSERS ..... Sept 83

Hall of Fame

Family Hall of Fame: Edwin Martin ..... Feb 28

Family Hall of Fame: Jan Little ..... Mar 16

Family Hall of Fame: Siegfried Pueschel ..... Apr/May 28

Health Care

Health Care Reform ..... Jul/Aug 26

Health Care Reform: Getting to the Heart of the Matter ..... Oct 28

Health Care Reform Initiative Launched ..... Nov/Dec 45

1993 Exceptional Parent Topical Index

Health Care Reform: What Does it Actually Say About Disabilities? ..... Nov/Dec 18
Health Care Reform: Write Now ..... Oct 42

Hearing Impairments

Audiology/Pathology Insurance Coverage ..... June 60
Deafness Center Publishes National Club Directory ..... June 60
Hearing Aid Bank ..... Mar 72
Hereditary Hearing Loss Research Registry ... Nov/Dec 48
How Does Your Child Hear and Talk? ..... Oct 59
National Information Clearinghouse on Deaf-Blind ..... Sept 92
Purchasing a Hearing Aid ..... Oct 44

Incontinence

Coping with Incontinence ..... Feb 30

Insurance

Audiology/Pathology Insurance Coverage ..... June 60
Insurance Claim Appeal ..... Mar 30
Labels Can Be Harmful ..... Jul/Aug 24

Learning Disabilities

ATA Scrapbook of Success ..... Apr/May 48
Attention Deficit Hyperactivity Disorder ..... Sept 64
Helping Children Overcome Learning Difficulties ..... Oct 36

Legislation

Family Hall of Fame: Edwin Martin ..... Feb 28
Family Support Legislation Drafted ..... Sept 86
Legislative Update ..... June 53
NPND Policy Statement on Education Reform ..... Mar 67
Parents' Voices Heard on the Hill ..... June 51

Mental Illness

Dually Diagnosed ..... June 60
Labels Can Be Harmful ..... Jul/Aug 24

Mental Retardation

ATA Scrapbook of Success ..... Jul/Aug 50
Dually Diagnosed ..... June 60
Family Hall of Fame: Siegfried Pueschel ..... Apr/May 28
Family Support Action Pack ..... Oct 58
Physical Activity for Individuals with Mental Retardation ..... June 58
Profound Truths ..... Feb 20
Tough Choice ..... Apr/May 24

Mobility

Adventures in Camping ..... Apr/May 20
Aquatic Sports ..... Jul/Aug 30
Auto Industry Offers Incentives ..... Jul/Aug 46
European Camping Holidays Available ..... Feb 55
Making Your Home Work—Ramps ..... Apr/May 30
School Bus Safety Dispute ..... Mar 74
Selecting a Seating System ..... June 42
Study on Bus Access Released ..... Oct 58
Tax on Customized Vehicles Repealed .... Nov/Dec 47/54
When Your Child Goes to School After an Injury: Getting To and From School Safely ..... Mar 62/June 55
Update on School Bus Safety ..... Oct 46

Multiculturalism

Multiculturalism and Disability ..... Mar 70

Orthotics

Information Available About Prosthetics and Orthotics ..... Apr/May 50

Parent/Professional Relationship

Effective Parent Advocacy: How to Take Charge ..... Sept 73
Labels Can Be Harmful ..... Jul/Aug 24
Meetings Are Always Unpleasant For Us ..... Mar 80
Neuromuscular Disease Referral Program ..... Mar 72
Parent-Teacher Cooperation—A Shared Responsibility ..... Sept 31
We Continued the School People's Fight at Home ..... Feb 48
When Your Child Goes to School After an Injury: From Hospital to School ..... Apr/May 44

Parenting

Baby Girl ..... Mar 34
Developing Your Own IEP ..... Oct 40
Effective Parent Advocacy: How to Take Charge ..... Sept 73
Family Support Programs Growing ..... Jul/Aug 36
Finding the Fun ..... Jul/Aug 32
Fine Purpose, A ..... Oct 23
Images of Fathers ..... Oct 49
Learning to See the Bright Side ..... Jul/Aug 16
Merry-Go-Round, The ..... June 20
Miracles of Brea, The ..... Apr/May 22
On the Ice ..... Feb 42
One Miracle at a Time ..... Feb 52
Papa's Sweetheart ..... June 16
Parent to Parent National Survey ..... Nov/Dec 42
Reflections on a Birthday ..... Nov/Dec 39
Residential Placement: Coping with Separation ..... Sept 67

1993 Exceptional Parent Topical Index

Silent Ringmaster, The ..... Nov/Dec 40
We Continued the School People's Fight at Home ..... Feb 48

Physical Disabilities

A Place in the Dugout: Family Mainstreaming in a Rural Community ..... Sept 78
ATA Scrapbook of Success ..... Feb 45
ATA Scrapbook of Success ..... June 56
Baby Girl ..... Mar 34
David Should Have a Graduation Party, Too ..... June 62
Home Beach ..... June 28
Insurance Claim Appeal ..... Mar 30
Learning to See the Bright Side ..... Jul/Aug 16
Merry-Go-Round, The ..... June 20
Miracles of Brea, The ..... Apr/May 22
New Technology for Artificial Arms ..... Nov/Dec 24
Papa's Sweetheart ..... June 16
Profound Truths ..... Feb 20
Reaching Out ..... Jul/Aug 20
Spinal Cord Injury Information Database Now On-Line ..... June 60

Prostheses

Information Available About Prosthetics and Orthotics ..... Apr/May 50
New Technology for Artificial Arms ..... Nov/Dec 24

Recreation

1992 Summer Program Awards ..... Apr/May 18
1992 Summer Program Awards ..... June 24
A Place in the Dugout: Family Mainstreaming in a Rural Community ..... Sept 78
Aquatic Sports ..... Jul/Aug 30
Deafness Center Publishes National Club Directory ..... June 60
EP's Guide to Summer Fun ..... Apr/May 36
Home Beach ..... June 28
Leisure Experience ..... June 54
Physical Activity for Individuals with Mental Retardation ..... June 58

Residential Care

Liberty and Choices for All ..... June 14
Profound Truths ..... Feb 20
Residential Placement: Coping with Separation ..... Sept 67
Tough Choice ..... Apr/May 24

Seating/Positioning

Selecting a Seating System ..... June 42

Sibling Relationships

Ashley Nicole Howard ..... Jul/Aug 68
My Sisters ..... Feb 68
It Isn't Fair ..... Jul/Aug 56
My Best Friend ..... Apr/May 68
My Sister and I ..... Mar 92
Ryan ..... June 76
When Your Child Goes to School After an Injury, Preparation and Communication Between Families and Schools ..... Jul/Aug 53

Social Skills

A Place in the Dugout: Family Mainstreaming in a Rural Community ..... Sept 78
Circle of Friends ..... Feb 24

Technology

ATA Scrapbook of Success ..... Feb 45
ATA Scrapbook of Success ..... Mar 79
ATA Scrapbook of Success ..... Apr/May 48
ATA Scrapbook of Success ..... June 56
ATA Scrapbook of Success ..... Jul/Aug 50
ATA Scrapbook of Success ..... Feb 45
Getting Started with Computers ..... Nov/Dec 27
Technology Use at Home ..... Nov/Dec 36
Telecommunications ..... Nov/Dec 62

Tips for Parents

A Personal Beeper Can Buy Parents Peace of Mind ..... Mar 90
Adapting Sports Rules ..... June 70
Cart Promotes Independence ..... June 70
Mealtime Platform ..... Jul/Aug 58
Sledding on the Beach ..... Jul/Aug 58
Special Bed Keeps Children in at Night ..... Jul/Aug 58
Teaching With the VCR ..... June 70

Toys, Games

A Handful of Fun with *Slap Happy* ..... June 71
Choosing Holiday Toys ..... Oct 19
Drawing with *Spirograph Suspension Art* ..... Feb 66
Going Bananas with *Monkey Mania* ..... Apr/May 67
Knocking Down Blocks with *Knock-Out* ..... Mar 91
Spills and Thrills with *Stretch-Out Sam* ..... Jul/Aug 66

Transportation

Auto Industry Offers Incentives ..... Jul/Aug 46
Legislative Update ..... Mar 69
School Bus Safety Dispute ..... Mar 74
Study on Bus Access Released ..... Oct 58
Tax on Customized Vehicles Repealed ..... Nov/Dec 47/54

Update on School Bus Safety ..... Oct 46
When Your Child Goes to School After an Injury. Getting To and From School Safely ..... Mar 62/June 55

Travel

Adventures in Camping ..... Apr/May 20
EP's Guide to Summer Fun ..... Apr/May 36
European Camping Holidays Available ..... Feb 55
International Exchange Program Recruits Delegates ..... Feb 55
New Tactile Guide to Washington, DC ..... Feb 55

Video

Teaching With the VCR ..... June 70

Visual Impairments

ATA Scrapbook of Success ..... Apr/May 48
Braille Children's Anthology ..... Mar 72
Careers and Technology Information Bank ..... Sept 92
National Information Clearinghouse on Deaf-Blind ..... Sept 92
National Registry for Retinopathy of Prematurity ..... Sept 92
New Tactile Guide to Washington, DC ..... Feb 55

PI BEAR KNOWS

(Physically Inconvenienced)

PI BEAR knows what it's like to be scared. Through PI BEAR's three storybooks (included in his chair backpack) about his own accident, struggles, and triumphs he can help a disabled child understand his or her feelings of fear and uncertainty. And when his beary special friendship is needed, PI BEAR will be there. PI and his wheelchair are approximately 14" tall. He also comes with a club membership certificate and a one-year warranty. Call 800-467-BEAR (2327) to order. Visa and Mastercard accepted. ©

PI BEAR™

Circle #123

NATIONALLY RECOGNIZED EDUCATION AND TREATMENT FACILITY

Serving children young adults with autism and other developmental disabilities.

- Residential and day services
- Relaxation, imagery and other positive self-control techniques
- Academic and vocational programs
- Supported employment
- Small, personal client residences
- Highly trained and devoted staff

The Groden Center, Inc.
86 Mount Hope Ave.
Providence, RI 02906
(401) 274-6310

Circle #88

Rifton
FOR PEOPLE WITH DISABILITIES

Because you care

Circle #66

FREE CATALOG
BOX 901 RIFTON, NY 12471 800/374-3866

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or Product & Service listing or refer to the Directory of Advertisers.

2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.

3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.

4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

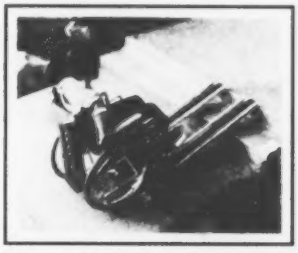
EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

Rollup/3' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

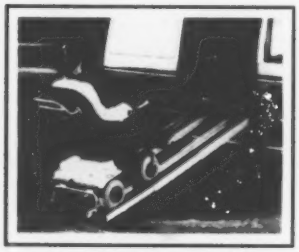
- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

Look for this Seal of Quality



R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle #40

DIRECTORY OF ADVERTISERS

Circle #	Advertiser	Page #
#9	AccessAble Environments	22
#3	Adaptive Design	28
	Apple	40-41
#7	BHC JA Preston	back cover
#6	Berkshire Meadows	47
#8	Bruno	30
#10	Charles C. Thomas	54
#11, #12, #13	Columbia Medical	21, 23, 52
#14	CompCare	56
#16	Convaid	39
#17	Crotched Mountain	45
#18	Cumberland	24
#19	Devereux	53
#20	Duraline	8
#25	Equipment Shop	42
#26	Estate Planning	42
	Exceptional Parent Library	75
#27	Evergreen	28
#29	Flaghouse	28
#30	Ford	inside front cover
#34	GMR Labs	22
#33	Genetics & IV Institute	66
#87	Global Export Marketing	30
#88	Groden Center	63
#37	HDIS	30
#39	HMS School	65
#36	Haverich Ortho-Sport, Inc.	22
#38	Heartspring	8
#40	Homecare Products, Inc.	64
#41	Imaginart	42
#42, #43	Innovative Products	27, 56
#89	Interior Planning & Design	28
#45	Kennedy Krieger	42
#48	Laureate Learning	48
#51	M. J. Markell Shoe Co.	21
#1	N/R Labs	23
#55	New England Villages	46
#57	Oticon, Inc.	inside back cover
#60	Phonic Ear	23
#123	PI Bear	63
#61	Prentke Romich Co.	52
#103	Rhamdec	3
#65	Ricon	29
#66	Rifton	63
#67	Rollins Healthcare	58
#73	St. Colletta (of MA)	46
#74	St. Colletta (of WI)	48
#75	St. John's Villa	46
#68	Sentient Systems	9
#69	Snug Seat	10
#71	Special Design	7
#76	Starlight Footwear	51
#77	Stewart Home School	48
#78	Stroller Pack	51
#101, #102	TASH	52,56
#82	Triaid, Inc.	72
#84	Voicing	65
#85	Voorhees Pediatric	56
#86	Woodbury Products	21

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date January 31,1994

Expiration Date December 31, 1994

Circle

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date January 31,1994

Expiration Date December 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

EXCEPTIONAL PARENT

Parenting Your Child With A Disability

Vice President Advertising Sales
Kerry J. Cannon
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/Fax (201) 489-1240

Sales Representatives

Greater New York - Joni Jones
Phone (516) 944-8068/Fax (516) 944-2739

New Jersey: Schools, Camps, Residences, Classified & Special Sales - Barbara Nastro
Phone (201) 680-4874/Fax (201) 680-8355

New England, Upstate NY and East Canada - Barbara H. Arnold
Phone (617) 259-9207/Fax (617) 259-9883

MidAtlantic (DE, DC, MD, PA, VA, WV) - J. Ronald Doran
Phone (908) 741-6869/Fax (908) 530-8216

Southeast (AL, FL, GA, MS, NC, SC, TN) - William Middleton
Phone (404) 973-9190/Fax (404) 859-0051

Midwest (IN, KY, KS, MN, ND, OH, SD, UT, CO) - Anthony Arnone
Phone & Fax (708) 428-5162

Midwest (IL, IO, NE, MO, MI) - John Maisel
Phone (708) 416-0780/Fax (708) 416-0793

Southwest (AZ, NM, TX, OK, LA, AR) - Sherylen Young
Phone (602) 991-2889/Fax (602) 596-4026

West Coast (So CA, NV) - Richard Ayer
Phone (714) 366-9089/Fax (714) 366-9289

West Coast (No CA, OR, WA, HI, BC) - William Hague
Phone (206) 858-7575/Fax (206) 858-7576

Ad Traffic Manager
Stefanie Ferrante
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/Fax (201) 489-1240

BPA International Consumer Magazine Membership Applied for August 1993.

Subscriptions:
Exceptional Parent
P.O. Box 3000, Dept. EP, Denville, NJ 07834
(800) 247-8080 (New subscriptions ONLY)
(800) 562-1973 (Customer Service)

EDITORIAL INFORMATION: Contact Dr. Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

Voicing! Announces
Therapy Toy Products For Children with Tracheostomies

Meet Toby Tracheasaurus™

Toby Tracheasaurus™ is a plush toy including tracheostomy tube flange, speaking valve and tracheostomy tube tie. Toby provides parents, children and therapists with a light hearted therapy introduction.

Meet Toby's friends Tammy, Tex T-Rex, Baby Bronchiosaurus, Taylor Triceratops, Tina Talkasaurus, Stacey Speechosaurus, Trevor Talkadactil, and Violet Voiceasaurus in a new therapeutic coloring book.

Toby Tracheasaurus™ also has an Exhalation Therapy Kit. Each kit contains a variety of toys including whistles, pinwheels, bubbles and much, much more. This dinosaur theme is designed to assist with oral exhalation retraining and therapy motivation.

We Are Also Proud to Annouce Our New Textbook

Speech Pathology for Tracheostomized and Ventilator Dependent Patients
by Mary F. Mason M.S., CCC-SLP

This is the first comprehensive text that greatly expands on the material offered in the popular national series of *Voicing!* seminars "Communication Options for the Tracheostomized and Ventilator Dependent." This text provides state of the art assessment and treatment interventions in communication and swallowing disorders as well as an extensive background on airway management and mechanical ventilation issues.

For more information contact: *Voicing!*
3857 Birch, Suite 194, Newport Beach, CA 92660 • (714) 833-1005 •(714) 833-1005 FAX

Circle #84

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle #39

SLOW LEARNER? ATTENTION DISORDER?

These common problems affect many of America's children. Recent advances in medical genetic research now make it possible to identify those children suffering from **fragile X** syndrome, a frequent cause of learning disability, attention deficit disorder, and mental retardation. Accurate diagnosis opens the door to optimal treatment, and provides important information and answers to the children's families.

Although doctors have known about this condition for many years, accurate testing was not widely available. Now, a new **fragile X** test using DNA analysis permits rapid, accurate testing for this disorder. It also identifies those people who are genetic carriers of **fragile X**.

The GENETICS & IVF INSTITUTE, an internationally known center for medical genetic evaluation and testing, is a leader in the introduction of **fragile X** analysis in the United States. Testing is done on small blood samples which can be safely shipped in containers provided by the Institute. As with any medical laboratory testing, samples must be obtained and sent to us under the direction of a physician.

Please write or call for further information about **fragile X** testing. We are committed to parental and professional education about this important problem.

GENETICS & IVF INSTITUTE
3022 Javier Road,
Fairfax, Virginia 22031
1-800-654-GENE

Circle #33

Directory of Products and Services

AUGMENTATIVE COMMUNICATION

Consultants for Communication Technology
508 Bellevue Ter
Pittsburgh, PA 15202
(412) 761-6062
(412) 761-7336 (FAX)
For free information circle 15 on Reply Card.

Franklin Electronic Publisher
122 Burrs Rd
Mt. Holly, NJ 08060
(609) 261-4800
(609) 261-1631 (FAX)
For free information circle 150 on Reply Card.

GMR Labs
1030 E El Camino Real, #308
Sunnyvale, CA 94087
(408) 985-7200
(408) 243-3731 (FAX)
See our ad on page 22.

Imaginart
307 Arizona St
Bisbee, AZ 85603
(602) 432-5741
(602) 432-5134 (FAX)
See our ad on page 42.

Luminaud Inc
8688 Tyler Blvd
Mentor, OH 44060
(216) 255-9082
(216) 255-2250 (FAX)
For free information circle 50 on Reply Card.

Phonic Ear Inc
3880 Cypress Dr
Petaluma, CA 94954-7600
(800) 227-0735
(707) 769-9624 (FAX)
See our ad on page 23.

Prentke Romich Co
1072 Heyl Rd
Wooster, OH 44691
(800) 262-1984
(216) 263-4829 (FAX)
See our ad on page 52.

Sentient Systems Technology Inc
2100 Wharton St
Pittsburgh, PA 15237
(800) 344-1778
(412) 381-5241 (FAX)
See our ad on page 9.

Synergy
68 Hale Rd
E Walpole, MA 02032
(508) 668-7424
(508) 668-4134 (FAX)
For free information circle 79 on Reply Card.

Wayne County R.E.S.A.—Adamlab
33500 Van Born Rd
Wayne, MI 48184
For free information circle 105 on Reply Card.

BATHROOM EQUIPMENT

AccessAble Environments & Products
111 Cedar St
New Rochelle, NY 10801
(800) 285-2525
(914) 632-1357 (FAX)
See our ad on page 22.

The Adaptive Design Shop
12847 Pt Pleasant Dr
Fairfax, VA 22033
(703) 631-1585
See our ad on page 28.

Andermac
2626 Live Oak Hwy
Yuba City, CA 95991-8810
(800) 824-0214
(916) 674-1806 (FAX)
For free information circle 4 on Reply Card.

Aquatec Health Care Products L.P.
1003 International Dr
Oakdale, PA 15071-9223
(412) 695-2122
(412) 695-2922 (FAX)
For free information circle 128 on Reply Card.

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(310) 454-6612
(310) 305-1718 (FAX)
See our ad on pages 21, 23, 52.

J. A. Preston Corp
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
(800) 245-3765 (FAX)
See our ad on the back cover.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 95 on Reply Card.

Rifton Equipment
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8065 (FAX)
See our ad on page 63.

BEDDING

Hard Manufacturing Co Inc
230 Grider St
Buffalo, NY 14215
(800) USE-HARD

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

CATALOGS

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(310) 454-6612
(310) 305-1718 (FAX)
See our ad on pages 21, 23, 52.

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 107 on Reply Card.

Edmark Corporation
6727 185th Ave NE
Redmond, WA 98052
(800) 362-2890;
(206) 556-8430 (FAX)
For free information circle 23 on Reply Card.

Flaghouse Inc
150 N MacQuesten Pkwy
Mt. Vernon, NY 10550
(914) 699-1900
(914) 699-2961 (FAX)
See our ad on page 28

Imaginart
307 Arizona St
Bisbee, AZ 85603
(602) 432-5741
(602) 432-5134 (FAX)
See our ad on page 42.

Directory of Products and Services

CLOTHING

M. J. Markell Shoe Company Inc
PO Box 246, Main Station
Yonkers, NY 10702-0246
See our ad on page 21.

Special Clothes
PO Box 4220
Alexandria, VA 22303
(703) 683-7343
(703) 549-2640 (FAX)
For free information circle 70 on Reply Card.

Starlight Footwear Collection
21537 Kapok Cir
Boca Raton, FL 33433
(800) 55-SHOES
See our ad on page 51.

COMMUNICATION AIDS

Care Electronics
5741 Arapahoe Rd, Ste 2A
Boulder, CO 80303
(303) 444-CARE (2273)
For free information circle 138 on Reply Card.

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 108 on Reply Card.

Don Johnson Developmental Equipment
PO Box 639
Wauconda, IL 60084-0639
(708) 526-2682
For free information circle 139 on Reply Card.

Imaginart
307 Arizona St
Bisbee, AZ 85603
(602) 432-5741
(602) 432-5134 (FAX)
See our ad on page 42.

Luminaud Inc
8688 Tyler Blvd
Mentor, OH 44060
(216) 255-9082
(216) 255-2250 (FAX)
For free information circle 49 on Reply Card.

Marblesoft
12301 Control Ave NE
Blaine, MN 55434
(612) 755-1402
For free information circle 136 on Reply Card.

Tash Inc
Unit 1, 91 Station St
Ajax, ON
Canada L15 3H2
See our ad on pages 52, 56.

Voicing! Inc
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (FAX)
See our ad on page 65.

COMPUTER HARDWARE

Apple Computer
20525 Mariani Ave
Cupertino, CA 95014
(800) 538-9696 ext 215
See our ad on page 40-41.

Edmark Corporation
6727 185th Ave NE
Redmond, WA 98052
(800) 362-2890
(206) 556-8430 (FAX)
For free information circle 24 on Reply Card.

IBM (Special Needs Systems)
1000 NW 51st St
Boca Raton, FL 33429
(407) 982-9099
(407) 982-6059 (FAX)
For free information circle 121 on Reply Card.

Prentke Romich Co
1072 Heyl Rd
Wooster, OH 44691
(800) 262-1984
(216) 263-4829 (FAX)
See our ad on page 52.

Synergy
68 Hale Rd
E Walpole, MA 02032
(508) 668-7424
(508) 668-4134 (FAX)
For free information circle 80 on Reply Card.

COMPUTER SOFTWARE

Don Johnson Developmental Equipment
PO Box 639
Wauconda, IL 60084-0639
(708) 526-2682
For free information circle 140 on Reply Card.

E.C.S. Exceptional Children's Software
PO Box 487
Hays, KS 67601
(913) 625-9281
For free information circle 28 on Reply Card.

Edmark Corporation
6727 185th Ave NE
Redmond, WA 98052
(800) 362-2890
(206) 556-8430 (FAX)
For free information circle 22 on Reply Card.

Laureate Learning Systems Inc
110 E Spring St
Winooski, VT 05404
(800) 562-6801
(802) 655-4757 (FAX)
See our ad on page 48.

Marblesoft
12301 Control Ave NE
Blaine, MN 55434
(612) 755-1402
For free information circle 137 on Reply Card.

Microsystems Software
600 Worcester Rd
Framingham, MA 01701
(508) 879-9000

Prentke Romich Co
1072 Heyl Rd
Wooster, OH 44691
(800) 262-1984
(216) 263-4829 (FAX)
See our ad on page 52.

UCLA Intervention Program
UCLA/LAUSD Microcomputer Project
1000 Veteran Ave, Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
For free information circle 83 on Reply Card.

ENVIRONMENTAL CONTROLS

Quartet Technology Inc
7565 Tiptoe Ln
Cupertino, CA 95014
(408) 253-1971 (West; Voice/FAX);
(508) 692-9313 (East)
For free information circle 64 on Reply Card.

Tash Inc
Unit 1, 91 Station St
Ajax, ON
Canada L15 3H2
See our ad on pages 52, 56.

Teledynn Brown Engineering (Imperium)
300 Sparkman Dr NW
Huntsville, AL 35807
(205) 726-6745
(205) 726-6739 (FAX)
For free information circle 120 on Reply Card.

ESTATE PLANNING

Estate Planning for Persons with Disabilities (National Office)
3100 Arapahoe Ave, Ste 112
Boulder, CO 80303
(800) 448-1071
(303) 449-6003 (FAX)
See our ad on page 42.

FEEDING AIDS

Equipment Shop
PO Box 172
Bedford, MA 01730
(617) 275-7681
(617) 275-4094 (FAX)
See our ad on page 42.

Imaginart
307 Arizona St
Bisbee, AZ 85603
(602) 432-5741
(602) 432-5134 (FAX)
See our ad on page 42.

Ross Products Division of Abbott Laboratories
625 Cleveland Ave
Columbus, OH 43226
(800) 544-7495
For free information circle 126 on Reply Card.

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

FOOD, SPECIAL

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

FURNITURE

The Boling Company, Furniture Manufacturer
2 Annabelle Ln
Florham Park, NJ 07932
(201) 966-0220
(201) 966-6894 (FAX)
For free information circle 81 on Reply Card.

Interior Planning & Design Inc
2 Annabelle Ln
Florham Park, NJ 07932
(201) 966-0220
(201) 966-6894 (FAX)
See our ad on page 28.

Rhamdec Inc/MYDESC
476 Ellis St
Mountain View, CA 94043-2240
(800) 4-MYDESC
(415) 965-3251
(415) 965-0705 (FAX)
See our ad on page 3.

HEADGEAR

Ortho-Kinetics inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 97 on Reply Card.

Plum Enterprises Inc
PO Box 283
Worcester, PA 19490
(800) 321-PLUM
(215) 584-4151 (FAX)
For free information circle 130 on Reply Card.

HEARING AIDS, EQUIPMENT

Oticon Inc
29 Schoolhouse Rd
Somerset, NJ 08875
(800) 227-3921 ext 535
See our ad on the inside back cover.

HOME HEALTH CARE

AccessAble Environments & Products
111 Cedar St
New Rochelle, NY 10801
(800) 285-2525
(914) 632-1357 (FAX)
See our ad on page 22.

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(310) 454-6612
(310) 305-1718 (FAX)
See our ad on pages 21, 23, 52.

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 113 on Reply Card.

Maddak Inc
6 Industrial Rd
Pequannock, NJ 07440
(201) 628-7600
(201) 305-0841 (FAX)
For free information circle 153 on Reply Card.

N/R Laboratories Inc
900 E Franklin St
Centerville, OH 45459
(800) 433-9547
(513) 433-0779 (FAX)
See our ad on page 23.

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

INCONTINENCE

CompCare
5534 Cortez Rd W
Bradenton, FL 34210
(800) 877-7317
See our ad on page 56.

Duraline
324 Werner St
Leipsic, OH 45856
(800) 654-3376
See our ad on page 8.

H.D.I.S.
PO Box 52039
St. Louis, MO 63136
(314) 521-1380
For free information circle 145 on Reply Card.

Humanicare International Inc
1471 Jersey Ave
North Brunswick, NJ 08902
(800) 631-5270
(908) 214-0666 (FAX)
For free information circle 151 on Reply Card.

Incon Products Company
509 W 9th St
S Sioux City, NE 68776
(402) 494-1744 (FAX)

Kimberly Clark Corp
2 Neenah Center
Neenah, WI 54957-2006
(414) 721-8170
For free information circle 147 on Reply Card.

Principle Business Enterprises Inc
Pine Lake Industrial Pk
Dunbridge, OH 43414
(800) GO-PEACH (467-3224)
(419) 352-8340 (FAX)
For free information circle 63 on Reply Card.

Procter & Gamble
1 P & G Plaza
Cinncinati, OH 45202
(513) 287-1839
For free information circle 149 on Reply Card.

Techno Marketing Inc (TMI)
307 Bacon Rd
Rougemont, NC 27572
(919) 477-1387
For free information circle 122 on Reply Card.

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

INSURANCE

CIGNA
1 Liberty Pl
1650 Market St
Philadelphia, PA 19192-1550
(215) 761-1000
For free information circle 135 on Reply Card.

PERSONAL CARE

DeVilbiss Health Care Inc
PO Box 635
Somerset, PA 15501-0635
(814) 443-4881
(814) 443-7597 (FAX)
For free information circle 134 on Reply Card.

N/R Laboratories Inc
900 E Franklin St
Centerville, OH 45459
(800) 433-9547
(513) 433-0779 (FAX)
See our ad on page 23.

Nu-Tec Health Products Inc
5671 Palmer Wy, Ste D
Carlsbad, CA 92008
(800) 868-8338
(619) 720-2226 (FAX)
For free information circle 56 on Reply Card.

Woodbury Products Inc
4410 Austin Blvd
Island Park, NY 11558
(800) 879-3427
(516) 431-6793 (FAX)
See our ad on page 21.

PUBLISHERS

Charles C. Thomas
2600 S First St
Springfield, IL 62794
(800) 258-8980
(217) 789-9130 (FAX)
See our ad on page 54.

Interax Training Inc.
PO Box 473106
Garland, TX 75047
(800) 242-5583

Jason and Nordic Publishing
PO Box 441
Holidaysburg, PA 16648
(814) 696-4250 (FAX)

Paul H. Brookes Publishing Co
PO Box 10624
Baltimore, MD 21285
(410) 337-9530
(410) 337-8539 (FAX)

Special Needs Project
3463 State St
Santa Barbara, CA 93105
(800) 333-6867

Voicing! Inc
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (FAX)
See our ad on page 65.

Woodbine House
5615 Fishers Ln
Rockville, MD 20852
(800) 843-7323

RAMPS/LIFTS

AccessAble Environments & Products
111 Cedar St
New Rochelle, NY 10801
(800) 285-2525
(914) 632-1357 (FAX)
See our ad on page 22.

The Braun Corp
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(719) 946-4670 (FAX)
For free information circle 116 on Reply Card.

Bruno Independent Living Aids Inc.
1780 Executive Dr
PO Box 84
Oconomowoc, WI 53066
(800) 887-8183
(414) 567-4341 (FAX)
See our ad on page 30.

Flinchbaugh Co Inc
390 Eberts Ln
York, PA 17473
(717) 854-7720
(717) 843-7381 (FAX)
For free information circle 124 on Reply Card.

G.T. Fabrication Inc
601 Tunkhannook Ave
West Pittston, PA 18643
(717) 883-0775
(717) 883-2232 (FAX)
For free information circle 125 on Reply Card.

Handi-Move
982 Rt 1
Pine Island, NY 10969
(800) 724-5305
(914) 258-6500
(914) 258-6634 (FAX)
For free information circle 35 on Reply Card.

Homecare Products Inc
15824 SE 296th St
Kent, WA 98042
(800) 451-1903
(206) 630-8196 (FAX)
See our ad on page 64.

J. A. Preston Corp
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
(800) 245-3765 (FAX)
See our ad on the back cover.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 98 on Reply Card.

Ricon Corp
12450 Montague St
Pacoima, CA 91331
(818) 899-7588
(818) 890-3354 (FAX)
See our ad on page 29.

S. D. Enterprises
28936 Phillips St
Elkhart, IN 46514
(800) 373-3661
(219) 262-3324 (FAX)
For free information circle 118 on Reply Card.

RECREATION

Angletech
318 N Hwy 67
PO Box 1893
Woodland Park, CO 80866-1893
(800) 793-3038
(719) 687-7475 (FAX)
For free information circle 104 on Reply Card.

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 110 on Reply Card.

Equipment Shop
PO Box 172
Bedford, MA 01730
(617) 275-7681
(617) 275-4094 (FAX)
See our ad on page 42.

Flaghouse Inc
150 N MacQuesten Pkwy
Mt. Vernon, NY 10550
(914) 699-1900
(914) 699-2961 (FAX)
See our ad on page 28.

Haverich Ortho-Sport Inc
67 Emerald St
Keene, NH 03431
(603) 358-0438
(603) 358-7998 (FAX)
See our ad on page 22.

Quickie Designs
2842 Business Park Ave
Fresno, CA 93727-1328
(800) 456-8168
For free information circle 94 on Reply Card.

Stroller-Pack
134 N Franklin St
Juneau, AK 99801
(800) 487-9652
(907) 463-4889 (FAX)
See our ad on page 51.

SCHOOLS, CAMPS, RESIDENTIAL PROGRAMS

Annandale at Suwanee Inc
3500 Annandale Ln, Box 7
Suwanee, GA 30174
(404) 945-8381
See our ad on page 58.

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 01236
(413) 528-2523
See our ad on page 47.

Camp Huntington
PO Box 3789
Poughkeepsie, NY 12603
(914) 687-7840
See our ad on page 58.

Chapel Haven Inc
1040 Whalley Ave
New Haven, CT 06515
(203) 397-1714
For free information circle 142 on Reply Card.

Crotched Mountain Rehabilitation Center Inc
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311
See our ad on page 45.

Devereux
19 S Waterloo Rd
PO Box 400
Devon, PA 19333
(800) 345-1292 ext 3045
(215) 971-4600
See our ad on page 53.

The Duvall Home
3395 Grand Ave
PO Box 22036
Glenwood, FL 32722
(800) 358-0450
(904) 734-5504 (FAX)
See our ad on page 51.

Evergreen Center
345 Fortune Blvd
Milford, MA 01757
(508) 478-5597
See our ad on page 28.

The Groden Center Inc
86 Mount Hope Ave
Providence, RI 02906
(401) 274-6310
See our ad on page 63.

Heartspring
2400 Jardine Dr
Wichita, KS 67219
(316) 262-8271
(800) 835-1043
See our ad on page 8.

HMS School for Children with Cerebral Palsy
4400 Baltimore Ave
Philadelphia, PA 19104
(215) 222-2566
See our ad on page 65.

The Learning Center
411 Waverly Oaks Rd
Waltham, MA 02154
(617) 893-6000
See our ad on page 58.

New England Villages Inc
664EP School St
Pembroke, MA 02359
(617) 293-5461
See our ad on page 46.

South Shore Center for Brain Injured Children Inc
Braintree High School
128 Town St
Braintree, MA 02184
(617) 848-0285
For free information circle 141 on Reply Card.

St. Coletta School
W 4955 Hwy 18
Jefferson, WI 53549
(414) 674-4330
See our ad on page 48.

St. Coletta's of Massachusetts
400 Washington St
Hanover, MA 02339
(617) 826-6371
See our ad on page 46.

St. John's Villa
620 Roswell Rd NW
PO Box 457
Carrollton, OH 44615
(216) 627-9789
See our ad on page 46.

Shevet Achim & Yachad/NCSY
63-67 108th St
Forest Hills, NY 11375
(718) 997-1177
(212) 563-4000
See our ad on page 58.

The Stewart Home School
Box 20
Frankfort, KY 40601
(502) 875-4664
See our ad on page 48.

Voorhees Pediatric Facility
1304 Laurel Oak Rd
Voorhees, NJ 08043
(609) 346-3300
See our ad on page 56.

SEATING/ POSITIONING

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(310) 454-6612
(310) 305-1718 (FAX)
See our ad on pages 21, 23, 52.

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 111 on Reply Card.

Convaid Products Inc
PO Box 2458
Rancho Palos Verdes, CA 90274
(310) 539-6814
(310) 539-3670 (FAX)
See our ad on page 39.

Equipment Shop
PO Box 172
Bedford, MA 01730
(617) 275-7681
(617) 275-4094 (FAX)
See our ad on page 42.

Flaghouse Inc
150 N MacQuesten Pkwy
Mt. Vernon, NY 10550
(914) 699-1900
(914) 699-2961 (FAX)
See our ad on page 28.

Freedom Designs
2241 S Madera Rd
Simi Valley, CA 93065
(800) 331-8551
For free information circle 31 on Reply Card.

Invacare
899 Cleveland St
Elyria, OH 44036
(216) 329-6696
For free information circle 154 on Reply Card.

J. A. Preston Corp
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
(800) 245-3765 (FAX)
See our ad on the back cover.

Jay Medical Ltd
PO Box 18656
Boulder, CO 80308-8656
(800) 648-8282
(303) 442-5529
(303) 442-3855 (FAX)
For free information circle 44 on Reply Card.

Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(410) 550-9000
(410) 550-8217 (FAX)
See our ad on page 42.

Kid Kart
126 Rosebud St, #1
Belgrade, MT 59714
(406) 388-1080
For free information circle 46 on Reply Card.

Loyal LaPlante Supply Co
6702 E 11th St
Tulsa, OK 74112
(918) 835-6381

Mulholland Positioning Systems
PO Box 391
Santa Paula, CA 93060
(805) 525-7165
For free information circle 54 on Reply Card.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 99 on Reply Card.

Otto Bock Orthopedic Industry Inc
3000 Xenium Ln N
Minneapolis, MN 55441
(800) 328-4058
(800) 962-2549 (FAX)
For free information circle 58 on Reply Card.

Rifton Equipment
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8065 (FAX)
See our ad on page 63.

Special Design
PO Box 130
Gillette, NJ 07933
(908) 464-8825
See our ad on page 7.

Special Health Systems
90 Englehard Dr
Aurora, ON
Canada L4G 3V2
(905) 841-1032
(905) 841-6162 (FAX)
For free information circle 72 on Reply Card.

STANDING EQUIPMENT

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 112 on Reply Card.

J. A. Preston Corp
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
(800) 245-3765 (FAX)
See our ad on the back cover.

Mulholland Positioning Systems
PO Box 391
Santa Paula, CA 93060
(805) 525-7165
For free information circle 52 on Reply Card.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 100 on Reply Card.

Prime Engineering
4838 W Jacquelyn #105
Fresno, CA 93722
(209) 276-0991
(209) 276-3544 (FAX)
For free information circle 62 on Reply Card.

Quickie Designs
2842 Business Park Ave
Fresno, CA 93727-1328
(800) 456-8168
For free information circle 93 on Reply Card.

Rifton Equipment
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8065 (FAX)
See our ad on page 63.

TOYS AND HOBBIES

D. Brady & Associates
PO Box 487 EP
Flourtown, PA 19031
(215) 247-1588
(215) 247-4121 (FAX)
For free information circle 5 on Reply Card.

Innovative Products Inc
830 South 48th St
Grand Forks, ND 58201
(800) 950-5185
(701) 772-5284 (FAX)
See our ads on pages 27, 56.

PI Bear Co Inc
821 Main
PO Box 189
Lacrosse, KS 67548
(800) 467-2327
(913) 222-2535
(913) 222-3102 (FAX)
See our ad on page 63.

Voicing! Inc
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (FAX)
See our ad on page 65.

TRICYCLES

Triaid Inc
3 Commerce Dr
Comberland, MD 21502
(301) 759-3525
See our ad on page 72

View Point Manufacturing
PO Box 108
Spanish Fork, UT 84660
(801) 798-0181
For free information circle 119 on Reply Card.

VANS/ VAN CONVERSION

Action Mobility
1925 10th Ave N
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 (FL only)

Advanced Conversions
2105 N Beach St
Fort Worth, TX 76111
(817) 834-1003

Arcola Mobility
51 Kero Rd
Carlstadt, NJ 07072
(800) ARCOLA-1
(201) 507-8500

Barrier Free Systems Inc
165 Freeman's Bridge Rd
Scotia, NY 12302
(518) 346-4169

The Braun Corp
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(719) 946-4670 (FAX)
For free information circle 115 on Reply Card.

Chrysler P-Cap Resource
1220 Rankin St
Troy, MI 48083-6004
(800) 255-9877
(313) 597-3501 (FAX)
For free information circle 90 on Reply Card.

Crow River Industries Inc
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688
For free information circle 114 on Reply Card.

Drive Master Inc
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709

DuraMed Driving Systems Inc
1543 15th St
Augusta, GA 30901
(800) 637-1378

Ford Mobility Motoring Program
PO Box 529
Bloomfield Hills, MI 48303-9857
(800) 952-2248
See our ad on the inside front cover.

Forward Motions Inc
214 Valley St
Dayton, OH 45404
(513) 222-5001

General Motors Mobility Program
3044 W Grand Blvd
Detroit, MI 48202
(800) 323-9935
For free information circle 32 on Reply Card.

S. D. Enterprises
28936 Phillips St
Elkhart, IN 46514
(800) 373-3661
(219) 262-3324 (FAX)
For free information circle 117 on Reply Card.

Vantage Mini Vans
2441 E. Chambers
Phoenix, AZ 85040
(602) 243-2700
For free information circle 132 on Reply Card.

Directory of Products and Services

Volkswagen
3800 Hamlin Rd
Auburn Hills, MI 48326
(313) 340-5000
(313) 340-5025 (FAX)
For free information circle 146 on Reply Card.

WHEELCHAIRS

Atlantic Rehabilitation Inc
81 Rumford Ave
Waltham, MA 02254
(617) 894-0069

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 109 on Reply Card.

Convaid Products Inc
PO Box 2458
Rancho Palos Verdes, CA 90274
(310) 539-6814
(310) 539-3670 (FAX)
See our ad on page 39.

Damaco
20542 Plummer St
Chatsworth, CA 91307
(800) 432-2434
For free information circle 133 on Reply Card.

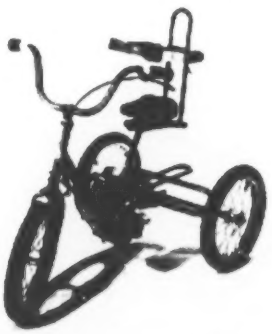
Dowd Rental
100 Main St
Buffalo, NY 14202
(716) 883-8188

Eagle Sportschairs
2351 Parkwood Rd
Snellville, GA 30278
(404) 972-0763
(404) 985-4885 (FAX)
For free information circle 21 on Reply Card.

Electric Mobility
1 Mobility Plz
Sewell, NJ 08088
(800) 662-4548
For free information circle 152 on Reply Card.

Everest & Jennings
1100 Corporate Square
St. Louis, MO 63132
(314) 995-7058
For free information circle 148 on Reply Card.

The Very Best Europe Has To Offer!



At American Prices.

TRIAID
REHABILITATION PRODUCTS

301-759-3525 Circle #82

P.O. Box 1364 Cumberland, Maryland 21502

VISA-MasterCard Now Available

Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Fortress
827 Jefferson Ave
Clovis, CA 93612
(209) 323-0292
For free information circle 131 on Reply Card.

Invacare
899 Cleveland St
Elyria, OH 44036
(216) 329-6696
For free information circle 143 on Reply Card.

Kushall of America
708 Via Alondra
Camarillo, CA 93012
(800) 654-4768
For free information circle 47 on Reply Card.

Mulholland Positioning Systems
PO Box 391
Santa Paula, CA 93060
(805) 525-7165
For free information circle 53 on Reply Card.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 96 on Reply Card.

Permobil Inc
6B Gill St
Woburn, MA 01801
(617) 932-9009
(617) 932-0428 (FAX)
For free information circle 59 on Reply Card.

Quickie Designs
2842 Business Park Ave
Fresno, CA 93727-1328
(800) 456-8168
For free information circle 92 on Reply Card.

Rehabco
1513 Olmstead Ave
Bronx, NY 14202
(718) 829-3800

Snug Seat
1081 Independence
Matthews, NC 28106
(704) 847-0772
See our ad on page 10.

Stroller-Pack
134 N Franklin St
Juneau, AK 99801
(800) 487-9652
(907) 463-4889 (FAX)
See our ad on page 51.

WHEELCHAIRS/ SCOOTERS

Amigo Mobility
6693 Dixie Hwy
Bridgeport, MI 48722
(800) 248-9130
For free information circle 144 on Reply Card.

Bruno Independent Living Aids Inc
1780 Executive Dr
PO Box 84
Oconomowoc, WI 53066
(800) 887-8183
(414) 567-4341 (FAX)
See our ad on page 30.

ALL OTHER SERVICES

Abledata
Database of Assistive Technology
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(301) 588-9284
(301) 587-1967 (FAX)
For free information circle 91 on Reply Card.

Cumberland Hospital for Children and Adolescents
PO Box 150
New Kent, VA 23124
(800) 368-3472
(804) 966-5639 (FAX)
See our ad on page 24.

Global Export Marketing (GEM)
International Marketing
2 Annabelle Ln
Florham Park, NJ 07932
(201) 966-0220
(201) 966-6894 (FAX)
See our ad on page 30.

LINCS-BBS
c/o Parents Helping Parents
Electronic Bulletin Board
535 Race St, #140
San Jose, CA 95126
(408) 294-6933 (BBS)
(408) 288-5010 (Voice)

Ross Products Division of Abbott Laboratories
Enteral Nutritional Products - Pediatrics & Adults
625 Cleveland Ave
Columbus, OH 43226
(800) 544-7495
For free information circle 127 on Reply Card.

80

Marketplace

Clothing

Adrian's Closet
PO Box 9506
Rancho Santa Fe, CA 92067
(800) 831-2577

Cribs & Youth Beds

HARD Manufacturing Co.,Inc
230 Grider St
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

Massachusetts

Atlantic Rehab Inc
81 Rumford Ave
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Dowd Rental & Sales
100 Main St
Buffalo, NY 14202
(716) 883-8188
Dowd has been servicing the area since 1930. For personal service and quality equipment and further information call Dowd Rental & Sales, Inc.

Rehabco®
1513 Olmstead Ave
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in childrens mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Oklahoma

Loyal LaPlante Supply Co.
6702 E 11th St
Tulsa, OK 74112
(918) 835-6381
Custom seating. Check Marc certified repairs. Authorized Check Marc Repair Center. We carry most products & advertised in this magazine.

Pennsylvania

Dowd Medical Equipment
904 Penn Ave
Pittsburgh, PA 15221
(412) 371-7300/(800) MED-DOWD
Trained professionals in custom, mobility, seating & positioning. A full service Dept. is available for modifications on site. Call for more info.

Grocery Services

Grocery Store to Your Door
PO Box 9001
Ft. Worth, TX 76147
(800) 460-7472 ext. 1000
Catalog ordering nonperishables: groceries, household cleaning, pet supplies, paper items, toiletries order from safety and convenience of your home. UPS to your door FREE. Low monthly fee and a way to earn money if interested. No more long lines, reclaim your free time.

Incontinence

Access Medical Supply
2006 Crown Plaza Dr
Columbus, OH 43235
(800) 242-2460
ATTENDS YOUTH BRIEFS. Fit children 35-75 lbs. $51.95/cs (96). Free Delivery. Mention this ad to receive a free tub of Attends Disposable Washcloths ($8.25 value) with your first order! We also carry Depend, Serenity, other items. Call for our Free Catalog!

Incon Products Company
509 W 9th St
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Quality Care Incontinence Products
PO Box 162
Woodstock, MD 21163
(800) 494-4984
Diapers/Briefs up to 48" waist; Training Pants to 42", Overnight Pants 20"-44"; Bed Pads; Flushable Liners. Prints available!

Top Drawers
901½ Main St
Hopkins, MN 55343
(612) 933-8231
TOP DRAWERS offers waterproof products for girls and boys of all ages and adults. 100% cotton diapers and bright colorful nylon covers are washable and reusable. Discreet home delivery. Free catalog available. Please call for more information.

Monitoring Systems

Care Electronics
5741 Araphoe Rd, Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home.Locate them up to ONE MILE away. FREE catalog.

Resources/Special Needs

LINCS-BBS C/O PHP,
535 Race St, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Seating & Positioning

Patient Transfer
PO Box 421176
Los Angeles, CA 90042-1176
(800) 510-0051
Transfer-Belt padded four handled, makes transfer much easier. Gurney-chair wheelchair transforms into gurney, allows toileting thru seat.

Software

GW Micro
310 Racquet Dr
Fort Wayne, IN 46825.
Call (219) 483-3625.
People that are blind, visually impaired or learning disabled can benefit from GW Micro's Vocal-Eyes, Sounding Board and other products providing voice output on your PC computer.

Microsystems Software
600 Worcester Rd
Framingham, MA 01701
(508) 879-9000
HandiWARE enables and improves access to PC's for the mobility-impaired, speech-impaired and hearing-impaired. Works with off-the-shelf programs, generic switches & industry-standard speech synthesizers. $20-& 6.95 s&h. Please write to Micro-systems Software for more info.

Microsystems Software
600 Worcester Rd
Framingham, MA 01701
(508) 879-9000
MAGic & MAGic Deluxe magnify PC or laptop VGA/SVGA/XGA screen, text and graphics programs 2X. Deluxe magnifies text-based apps. up to 12X. Work with adapted access software. MAGic: $79. Deluxe: $295 plus $5 s&h. Please write to Microsystems Software for more info.

Sports & Recreation

KID-KART
126 Rosebud, Ste #1
Belgrade, MT 59714
(800) 388-5278
The Kid-E-Plus is a lightweight primary use chair sturdy enough to enable outdoor mobility. The Kid-E-Plus Modular Positioning System will accommodate special children within the full spectrum of severity, adjustable to allow growth. Two mobility bases available. Kid-Kart also makes custom positioning systems.

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

Florida

Action Mobility
1925 10th Ave N
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 in FL
Full or Mini-Van modifications. Scooter & wheelchair lifts, lifts, drop floor, raised roof, lockdowns, driving equipment. Install, customize, repair. All mfgs.

B & R Mobility Services Inc
914 E Skagway Ave
Tampa, FL 33604
(813) 933-5452
Complete mobility equipment dealer. NMEDA Quality Assurance Program. Charter member with 5 star rating. Call for information.

Georgia

DuraMed Driving Systems Inc
1543 15th St
Augusta, GA 30901
(800) 637-1378
Custom driving systems, whichr, scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Indiana

Alternative Mobility
28244 Clay St
Elkhart, IN 46517
(219) 293-0367
Van and auto modifications, lifts, tie downs, raised roof, lowered floors, driving aids. NMEDA Members. Please call for more information.

Forward Motions Inc
214 Valley St
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Kentucky

Forward Motions Inc
214 Valley St
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Massachusetts

NE Wheels
3 Dunham Rd
Billerica, MA 01821
(800) 886-9247
We will build to meet your needs. Complete repair service available. Complete line of automotive adaptive equipment.

New Jersey

Arcola Mobility
51 Kero Road
Carlstadt, NJ 07072
(201) 507-8500/(800)ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Marketplace

Drive-Master Inc
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

New York

Barrier Free Systems Inc
165 Freeman's Bridge Rd
Scotia, NY 12302
(518) 346-4169
We sell and install equipment in the aid of transportation for the physically challenged. For more information, give us a call!

Drive-Master Inc
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

Ohio

Forward Motions Inc
214 Valley St
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

TRI-STATE MOBILITY
Canton, OH (800) 343-3150
Toledo, OH (800) 345-3150
One of the largest inventories of used handicapped vans.
Nationwide delivery available on request. Dealer for all major mobility equipment. NMEDA Member - Quad specialists.

Pennsylvania

Drive-Master Inc
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

South Carolina

DuraMed Driving Systems Inc
1543 15th St
Augusta, GA 30901
(800) 637-1378
Custom driving systems, w/lchr, scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Texas

Advanced Conversions
2105 N Beach St
Fort Worth, TX 76111
(817) 834-1003
Guy Tucker, President. Adaptive vehicle modifications. NMEDA member. 6 yrs. in business. Buy-sell-trade-lease new and used equipment. Wheelchair/scooter lifts. 24 hour services. Sale/Service: Ricon, Bruno, Mobil-Tech, EMC, EZ Lock, MPD, MPS, Kneel KAR, Care Concepts.

LIFT AIDS INC
2381 Pecan Ct
Ft. Worth, TX 76117
(817) 834-3881
Metro (817) 429-7141
Mobility specialist for physically disabled. largest wheelchair lift installer in Ft. Worth mid cities area. Authorized dealer/installer for Ricon, Crow River, Mobil Tech, Handicaps, Braun, Vantage Mini Vans. 5 Star dealer/member of NMDA. Full repair & service since 1968.

Workshops

Maxi-Move Program
112 Mountain Rd
Linthicum, MD 21090
(410) 789-0241
Maxi-Move Program: "CP not necessary" workshops for parents with severely involved CP children; 6 months to age 6. Before intervention operation: MD; PA; FL; VA; monthly: MD; PA; FL; VA. Schedule and reg., include $25; please write to: MM, 112 Mountain Rd., Linthicum, MD 21090.

Books, Audio/Video & Educational Material

Books for Parents & Professionals

WALKABOUT "A story of ABILITIES:" the potential of your child. Reggie proves he is not a "forever child" with 1,300 mile hike around WA State. **$15** ppd. **Balance Pubs.**, P.O. Box 447-X, Pt. Angeles, WA 98362. % of proceeds to disabled (money back guarantee)

BORN THIS WAY: An inspirational story about a man battling Cerebral Palsy. Copies available for **$5.95**. Write to **Don Zivney**, 1600 Sherman Ave., Apt. 110, Stevens Point, WI 5448

Turtle Books provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to **Jason & Nordic Publishers,** P.O. Box 441 Hollidayburg, PA 6648 or FAX (814) 696-4250

Handicapped In Walt Disney World® is the complete access guide for children or adults with disabilities. Peter Smith, the author, is a paraplegic. 302 pgs. **$13.95** (s&h incl.). **Southpark Publishing Group, Inc.,** 4041 W. Wheatland Rd., Suite 156-359, Dallas, TX 75237. (800) 669-5657..

Free–The NEW Special Needs Project Book Catalog. The best books from all publishers about disabilities. Comprehensive resources for parents, children and professionals. **Special Needs Project,** 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1993 Special Needs Catalog features a collection of valuable books for children with disabilities and their parents on Down Syndrome, CP, autism, spec. ed. and more. Please contact **Woodbine House,** 5615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

Educational Material

Callirobics Unique handwriting exercises with music designed to improve eye-hand & small muscle coordination, in a "stress-free" method. Ages 4-7, **$14.95**, Ages 7-up **$21.95**. Incudes workbook & audio cassette. **Callirobics**, P.O. Box 6634, Dept. EP, Charlottesville, VA 22906. (800) 769-2891.

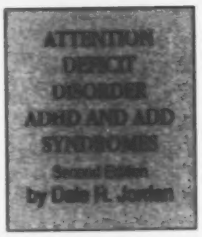
Videotapes

Interax Video Sign Language Course. Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

82

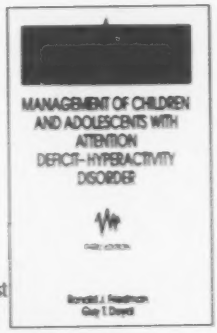
EXCEPTIONAL PARENT LIBRARY

ATTENTION DEFICIT DISORDER



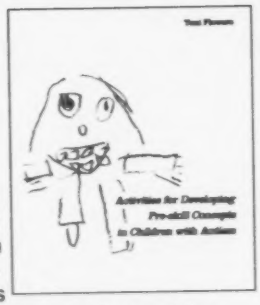
ATTENTION DEFICIT DISORDER ADHD AND ADD SYNDROMES
(Second Edition)
by Dale R. Jordan
(PE038AD) Book $14.00
(PE038) Videotape (50 minutes, 1/2" VHS) $98.00
This book describes how attention deficit-hyperactivity disorder (ADHD) and attention deficit disorder without hyperactivity (ADD) interfere with classroom learning, behavior at home, job performance and social skills development, and it gives guidelines for working successfully with ADHD and ADD in children, adolescents, and adults. Teachers, counselors, and parents will find this videotape to be informative and helpful in dealing with the ADD Syndrome child. Four types of ADD patterns are distinguished.

HELP! THIS KID'S DRIVING ME CRAZY! THE YOUNG CHILD WITH ATTENTION DEFICIT DISORDER
by Lynne Adkins and Janis Cady (Videotape) by Jane Judy, Lynne Aulkins and Janis Cady
(PE040AD) Book $5.00
(PE040) Videotape (13 minutes, 1/2" VHS) $89.00
This videotape presentation is designed to provide information about the nature and typical behavioral characteristics of young children with attention deficit disorder, to increase awareness of the special needs experienced by young children with attention disorder, and to offer suggestions on how to foster the development of appropriate behavior, including attention behavior. An attractive 64 page booklet, available separately, reiterates much of the important information covered in the program.

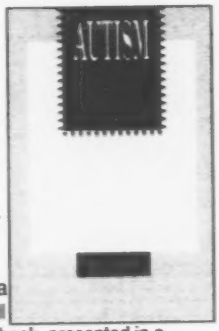


MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH ATTENTION DEFICIT-HYPERACTIVITY DISORDER
(Third Edition)
by Ronald J. Friedman and Guy T. Doyal
(PE039AD) $24.00
In this latest revision the authors combine the most current medical and psychological research findings with their 20 years' clinical experience with children with ADHD and their families. Written in a clear nontechnical manner, the book will be useful to parents, educators, and anyone interested in improving the lives of children with ADHD and their families.

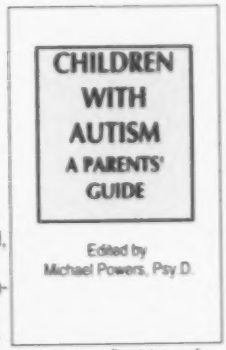
AUTISM



ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
by Toni Flowers
(PE035OD) $29.00
The activities in this practical book are in an easy-to-read format. Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels. The blackline masters are primarily for children with autism but can also be used with other severely handicapped children.



AUTISM INFORMATION AND RESOURCES FOR PARENTS, FAMILIES, AND PROFESSIONALS
by Richard L. Simpson and Paul Zionts
(PE043OD) $24.00
Parents and family members who experience the frustration, concern and uncertainty of living with a youngster with autism will appreciate this resource book, presented in a question-and-answer format. An appendix at the end of the text gives service organizations, professional periodicals, books, and videotapes where parents and other interested persons can find additional information on autism.

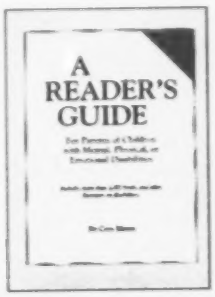


CHILDREN WITH AUTISM
A Parents' Guide
Edited by Michael Powers, Psy.D.
(WB017OD) 368 pp.
$14.95
Suggested by many as the first book on autism that families should read, CHILDREN WITH AUTISM provides a complete introduction to autism, while easing the family's fears and concerns as they adjust to and cope with their child's disorder. This book answers questions and gives hope to parents coping with this perplexing disorder. It is highly recommended reading for families.

WHEN SNOW TURNS TO RAIN
One Family's Struggle to Solve the Riddle of Autism
by Craig Schulze
(WB029AM) 216pp.
$14.95
WHEN SNOW TURNS TO RAIN is a father's moving personal account of his son Jordan's perplexing disorder — late onset autism. From Jordan's birth through his eighth year, Schulze describes his son's transformation from a happy, engaging toddler to a progressively disconnected child with autism. This poignant story echoes that of thousands of other families with children with autism.

DISABILITY, GENERAL

ADAPTIVE PLAY FOR SPECIAL NEEDS CHILDREN STRATEGIES TO ENHANCE COMMUNICATIONS AND LEARNING
by Caroline Ramsey Musselwhite
(PE042OD) $27.00
Adaptive play refers to play that has been altered in form, complexity, or intent to serve the needs of children with disabilities. This book summarizes recent advances in using play as a learning tool, developing adaptive play materials, teaching specific skills through play, and supporting the use of play in all settings.



A READER'S GUIDE FOR PARENTS OF CHILDREN WITH MENTAL, PHYSICAL, OR EMOTIONAL DISABILITIES
Third Edition
by Cory Moore
(WB032OD) 248 pp.
$14.95
A READER'S GUIDE is an indispensable tool for parents, teachers, and librarians — virtually anyone who needs to find the most current, authoritative information in print about children with disabilities. This useful annotated bibliography lists more than one thousand books and other resources on disabilities. Each listing has been carefully selected for parents.

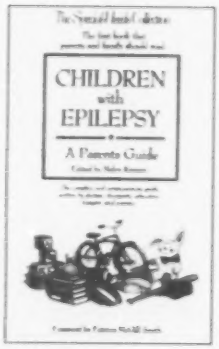
To order, use the order form on page 80, or call 1-800-535-1910

EXCEPTIONAL PARENT LIBRARY

CAN'T YOUR CHILD SEE? A GUIDE FOR PARENTS OF VISUALLY IMPAIRED CHILDREN
(Second Edition)
by Eileen P. Scott, James E. Jan, and Roger D. Freeman
(PE041OD) $23.00

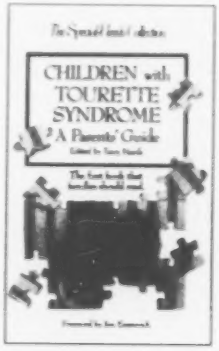
This second edition offers parents optimistic, practical guidelines for helping visually impaired children reach their full potential. The crucial role of parents is stressed, as is the need for their involvement and for support services. In easy-to-read language, the book examines the impact severe visual impairment can have on normal child development and offers realistic suggestions for managing related problems.

CHILDREN WITH EPILEPSY A PARENTS' GUIDE
Edited by Helen Reisner
(WB018OD) 314 pp. $14.95/



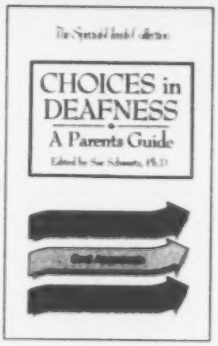
CHILDREN WITH EPILEPSY offers valuable direction and support to parents of a child with epilepsy. With chapters on diagnosis, medications, daily care, family life, advocacy, and special education, this book provides an in-depth look at epilepsy, and its various treatments, as well as its impact on the child and family.

CHILDREN WITH TOURETTE SYNDROME A PARENTS' GUIDE
Edited by Tracy Haerle
(WB016OD) 340 pp. $14.95



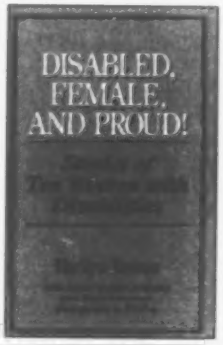
This parents' guide to Tourette Syndrome explains the disorder, including its symptoms, causes, and medications, as well as the disorders which are commonly linked with it. Other chapters cover family life, education, advocacy, and legal rights. Parent Statements appear throughout, offering insight, advice, and encouragement for the reader.

CHOICES IN DEAFNESS A PARENTS' GUIDE
by Sue Schwartz, Ph.D.
(WB025OD) 212 pp. $14.95



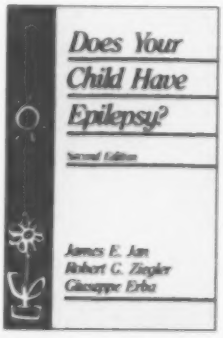
Parents of children with hearing impairments face a difficult decision — which method of communication is the most appropriate for their child? With its clear, objective descriptions of the three predominant communication methods, CHOICES IN DEAFNESS provides valuable guidance in sorting out the options.

DISABLED, FEMALE AND PROUD! STORIES OF TEN WOMEN WITH DISABILITIES
by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance
(GW003EP) $12.95
(Limited Supply)



Offers young women with disabilities empowering role models and the powerful message that they have full lives ahead of them. Offers parents and educators a unique way to help young people learn that making choices — about school, work, family, love — is what being disabled, female and proud is all about.

DOES YOUR CHILD HAVE EPILEPSY? (SECOND EDITION)
by James E. Jan, Robert G. Ziegler and Giuseppe Erba
(PE036OD) $22.00

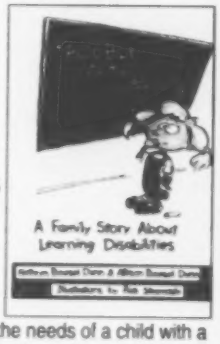


Written by three well-known pediatric specialists, this book provides information on the most common type of seizures, causes, principles of treatment, investigations and outcome, with a wide range of helpful suggestions from infancy to early adulthood. This book is highly recommended for parents and grandparents of children with epilepsy, older children with seizures and their siblings, teachers, health professionals, and other caregivers.

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
by Monte Mace
(TP026OD) $12.95

The Illustrated Directory empowers parents and persons with disabilities by widening choices about products. There are many products available — if you know where to find them. Sadly, many retail outlets do not carry a wide choice of products. This Directory shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

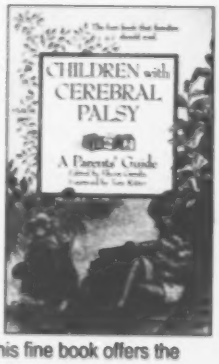
TROUBLE WITH SCHOOL A FAMILY STORY ABOUT LEARNING DISABILITIES
by Allison & Kathryn Dunn
(WB028LD) 32 pp. $9.95



TROUBLE WITH SCHOOL is an autobiographical tale about how one family handled the challenge of diagnosing and meeting the needs of a child with a learning disability (LD). The book's unique dual narrative allows the child and parent to take turns telling their side of the story. It takes a clear look at the warning signs and common problems associated with LD.

DISABILITY, PHYSICAL

CHILDREN WITH CEREBRAL PALSY A PARENTS' GUIDE
Edited by Elaine Geralis
(WB012PD) 434 pp.$14.95

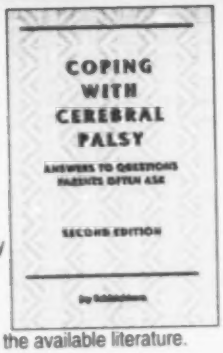


CHILDREN WITH CEREBRAL PALSY is essential reading for all parents who need to learn about CP and how it will affect their child and family. Written by doctors, therapists, educators, and parents, this fine book offers the perfect balance of information and support, presented in an easy-to-understand, compassionate style. It is an invaluable resource for families with a child with CP.

To order, use the order form on page 80, or call 1-800-535-1910

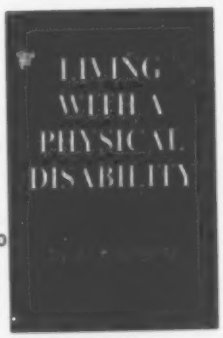
EXCEPTIONAL PARENT LIBRARY

COPING WITH CEREBRAL PALSY ANSWERS TO QUESTIONS PARENTS OFTEN ASK
(Second Edition)
by Jay Schliechkorn
(PE037PD) $24.00



Parents of children and adults with cerebral palsy often have many questions that are not satisfactorily answered by professionals or through the available literature. This book provides parents with answers to more than 300 questions that have been carefully researched and represents the author's 40 years of experience with parents of individuals with cerebral palsy. Appendixes include a glossary of terms, a listing of 60 special videotapes, and recommended readings.

LIVING WITH A PHYSICAL DISABILITY
by Jill Krementz
(SS014PD) $18.00



Portrays the indomitable spirit of children who live with disabilities. This book is an inspiring gift of hope from 12 children ranging in age from six to 16 whose physical disabilities include blindness, dwarfism, paralysis, birth anomalies, spasticity and CP. Captured in text and photos, these children tell their own stories and speak with candor about their lives.

TEACHING THE YOUNG CHILD WITH MOTOR DELAYS A GUIDE FOR PARENTS AND PROFESSIONALS
by Marci J. Hanson and Susan R. Harris
(PE049PD) $27.00

This easy-to-read guide bridges the gap between parents and professionals who work with movement-impaired children between the ages of birth and three years. The 228-page book has two purposes: to provide information to parents on how motor development influences other areas of child development and to provide teaching strategies and therapy activities for use in the home.

THE WHEELCHAIR TRAVELER®
by Douglass R. Annand
(WT015PD) $20.00

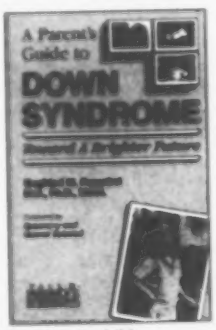
A practical dictionary of information for the traveler with a disability. Includes accessibility ratings of hotels/motels in the U.S., Canada and Mexico and useful tips for comfortable travel. Although written for adults, it provides helpful information for parents traveling with a child with a disability.

DOWN SYNDROME

ADVANCES IN DOWN SYNDROME
Edited by Valentine Dmitriev and Patricia L. Oelwein
(PE045DS) $31.00

Advances in Down Syndrome brings together over 20 expert physicians, counselors, educators, and nutritionists who contribute their recent research, experience, and thoughts on future directions for children with Down syndrome. The book pinpoints strategies in medicine, education, meeting special needs, parent involvement and living skills. Extensive and current references are provided.

A PARENT'S GUIDE TO DOWN SYNDROME TOWARD A BRIGHTER FUTURE
by Siegfried M. Pueschel, M.D., Ph.D., M.P.H.
(PB051DS) 315 pp./illus
$20.00

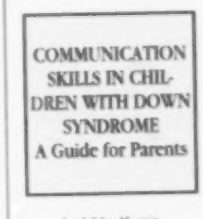


An easy-to-read, thorough overview of Down syndrome, this insightful resource will guide parents through the life span of their child. Dr. Pueschel, a leading authority in this field, sensitively explores such issues as reliable support services, sexuality and relationships, and career options to help parents give their child a chance for a full, independent life.

BABIES WITH DOWN SYNDROME A PARENTS' GUIDE
Edited by Karen Stray-Gundersen
(WB010MR) 237 pp.
$14.95

BABIES WITH DOWN SYNDROME is the complete guide for new parents of babies with Down syndrome. Written by professionals and parents, this book covers everything new parents need to know about rearing these children in a loving environment. Sensitive yet thorough, this book instills that essential "can-do" attitude by vanquishing every parent's greatest enemy: lack of information.

COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME A GUIDE FOR PARENTS
by Libby Kumin, Ph.D., CCC-SLP
(WB031DS) 237 pp.
$14.95



This is the first book to focus on speech and language development in children with Down syndrome. Parents learn how communication skills progress from infancy through the early teenage years and how Down syndrome can affect those skills. Chapters cover speech and intelligibility problems, evaluations, speech and language therapy, and communication needs in school and the community.

DOWN SYNDROME A RESOURCE HANDBOOK
Edited by Carol Tingey
(PE050DS) $22.00

This book, written for both families and clinicians, is personal in approach and direct in style. It discusses with compassion and knowledge the genetic, medical, social, and family aspects of Down syndrome.

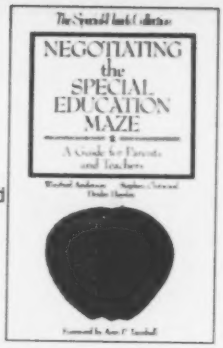
To order, use the order form on page 80, or call *1-800-535-1910*

EXCEPTIONAL PARENT LIBRARY

TEACHING THE INFANT WITH DOWN SYNDROME
A GUIDE FOR PARENTS AND PROFESSIONALS
(Second Edition)
by Marci J. Hanson
(PE048DS) $27.00

This expanded and thoroughly updated 268-page edition of the popular classic, *Teaching Your Down's Syndrome Infant*, is written specifically for the parents of Down syndrome infants. The bulk of the book consists of an extensively illustrated, step-by-step guide to recognizing and encouraging developmental milestones.

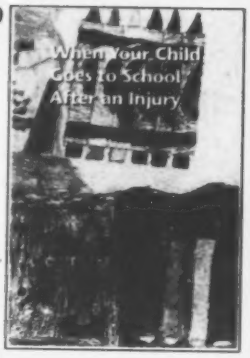
NEGOTIATING THE SPECIAL EDUCATION MAZE
A GUIDE FOR PARENTS AND TEACHERS
Second Edition
Anderson, Chitwood, and Hayden
(WB019OD) 269 pp.
$14.95



NEGOTIATING THE SPECIAL EDUCATION MAZE is an easy-to-follow guide to the special education system. By explaining each step of the process, this helpful book demystifies the system -- beginning with the very first evaluation through the design of the IEP. It also includes information about early intervention laws and services, plus a chapter on career education for older children.

INJURY

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY.
by Marilyn Lash
(EP006ML) $7.50
(includes s&h)



To guide parents through one of the most anguishing experiences a family can undergo, rehabilitation specialists at Tufts University School of Medicine and the New England Medical Center have produced a guide of practical, clear-eyed advice, written with input from parents with first-hand knowledge of the subject. Seventy-two pages long, *When Your Child Goes to School After an Injury* speaks in frank terms about the issues parents need to confront about their child's future schooling, health care and social needs.

EDUCATION

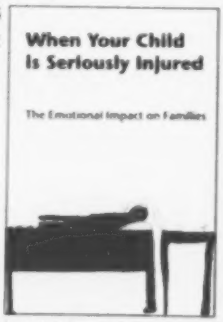
BY MYSELF BOOKS
by David Hooper and Ellie Reidlinger
(PE034EM) $21.00
each set of 10 books

By Myself Books motivate students to read independently. Each book is a short story (10-15 pages) with pictures on each page to help carry the story line. The content and format are associated with interests of students in kindergarten through second grade. *By Myself Books* are suitable independent reading for students labeled as language impaired, learning disabled, bilingual, or retarded readers. These books are packaged in two separate sets of 10 different titles each, in a colorful carrier bag. Set #1 is easier than Set #2.

THE LANGUAGE OF TOYS
TEACHING COMMUNICATION SKILLS TO SPECIAL-NEEDS CHILDREN
by Sue Schwartz, Ph.D. and Joan E. Heller Miller, Ed.M.
(WB020OD) 280 pp.
$14.95

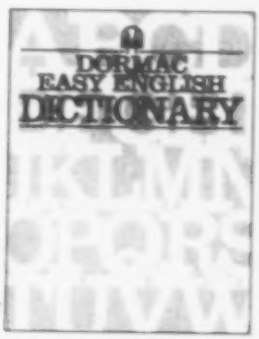
THE LANGUAGE OF TOYS teachers parents how to improve their child's communication skills at home with fun, easy-to-follow exercises. The activities and exercises use everyday toys, books, and games to stimulate speech and language development, so there is no need for specialized toys or equipment. This book is useful for all children with special needs.

WHEN YOUR CHILD IS SERIOUSLY INJURED: THE EMOTIONAL IMPACT ON FAMILIES
by Marilyn Lash
(EP005ML) $4.50
(includes s&h)



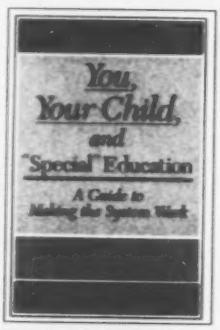
A 40-page practical guide discusses the hospitalization of injured children from arrival at the emergency room through discharge planning for rehabilitation and home. Topics include preparing for hospital visits, reaction to loss, helping siblings, and practical suggestions for coping. Developed by a Family Task Force, it includes a Parents' Bill of Rights, resource listings and suggested readings.

DORMAC EASY ENGLISH DICTIONARY
by Dorothee Baker and Constance Bettino
Edited by Dorothy McCarr, James E. McCarr, Lucille Eckert and Sara Natwick
(PE033EM) $19.00
(PE033) - Hardcover $29.00



The 512 page *Dormac Easy English Dictionary*, containing 5,000 entries, meets the needs of those who have limited reading and comprehension abilities. The large number of illustrations, combined with the controlled syntax and vocabulary in the definitions and usage sentences, make this dictionary invaluable to elementary and intermediate students with a reading level of approximately 1.0-4.0.

YOU, YOUR CHILD AND "SPECIAL EDUCATION": A GUIDE TO MAKING THE SYSTEM WORK
by Barbara Coyne Cutler, Ed.D.
(PB053OD) 249 pp.
$22.00



A vital handbook, this inspiring resource shows parents of children with disabilities how to obtain the educational services their child right-fully deserves. It examines the internal workings of the education system, reveals the challenges that await, lists the services that are available,and discusses the rights that are federally guaranteed.

MENTAL RETARDATION

CHILDREN WITH MENTAL RETARDATION
A PARENTS' GUIDE
Edited by Romayne Smith, M.A, CCC-SLP
(WB007MR) 437 pp.
$14.95

This book is a complete guide to everything parents need to know about raising their child and meeting her varied medical, therapeutic, and educational needs. Children with mild to moderate mental retardation, whether diagnosed at birth or in early childhood, require more help than usual in all areas of development, and their parents need to be well informed and involved every step of the way.

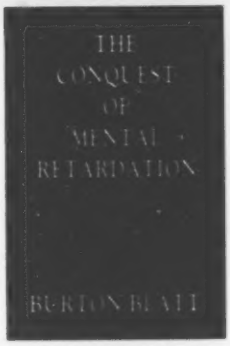
To order, use the order form on page 80, or call *1-800-535-1910*

EXCEPTIONAL PARENT LIBRARY

DIFFERENCES IN COMMON STRAIGHT TALK ON MENTAL RETARDATION, DOWN SYNDROME, AND LIFE
by Marilyn Trainer
(WB009MR) 236 pp.$14.95

In this engaging collection of essays, Marilyn Trainer draws on her experience as the mother of a child with Down syndrome, now in his twenties. With candor and humor, she brings a fresh, candid outlook to the challenges, hopes, and fears of family life — a life shaped by a child with Down syndrome, but one which strikes a common chord in all of us.

THE CONQUEST OF MENTAL RETARDATION
by Burton Blatt
(PE047MR) $38.00
(Hardcover)

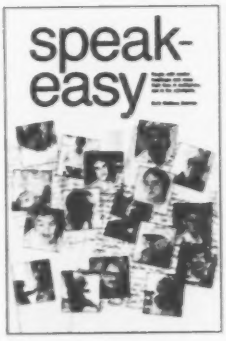


The author lays out the basics of the field — history, classification, and definitions — but he also discusses controversies; nature versus nurture, deinstitutionalization versus institutionalization, and the educability hypothesis. Moreover, each of these topics is placed within a broader context — social, political, and moral. A single, powerfully felt conviction infuses the whole: One's value as a human being does not have to be deserved.

IT ISN'T FAIR! SIBLINGS OF CHILDREN WITH DISABILITIES
Edited by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.
(EP001EP) $14.95

Includes all the material published in Exceptional Parent since 1971 on the topic of relationships between sisters and brothers when one child has a disability. Features chapters by parents, siblings and professionals.

SPEAKEASY PEOPLE WITH MENTAL HANDICAPS TALK ABOUT THEIR LIVES IN INSTITUTIONS AND IN THE COMMUNITY
by Karin Melberg Schwier
(PE044MR) $16.00



In this unique and compelling collection, people labeled mentally handicapped speak honestly and powerfully about their lives in large institutions and in the community. Through intimate interviews, the author has captured the dreams, fears, frustrations, and humor of people who were exiled for being different but battled social barriers to establish independence. Emerging from these pages are colorful, resilient, and thoughtful individuals.

GENERAL

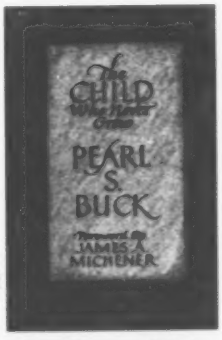
DEVELOPMENTAL DISABILITIES PSYCHOSOCIAL ASPECTS
by George S. Baroff
(PE046OD) $27.00

In this unusually perceptive book, the author conveys the psychological and social impact of developmental disability on the individual from infancy through adulthood. In the first section self-esteem is emphasized. The second section consists of an in-depth treatment of each of the major developmental disabilities; mental retardation, autism, cerebral palsy, and epilepsy. The last section is a brief epilogue in which the main psychosocial effects of developmental disabilities are summarized.

NOBODY'S PERFECT LIVING AND GROWING WITH CHILDREN WHO HAVE SPECIAL NEEDS
by Nancy B. Miller, Ph.D., M.S.W., with "The Moms"
(PB052OD) 307 pp./illus $21.00

This innovative book offers parents of children with special needs the strategies and emotional support to create a harmonious daily life and improved communication with family, relatives and professionals. The easy-to-read chapters guide parents through the four stages of adaption with candid, inspiring, and often humorous reflections of four mothers of children with special needs.

THE CHILD WHO NEVER GREW
by Pearl S. Buck
Foreword by James A. Michener
(WB008MR) 107 pp. $14.95

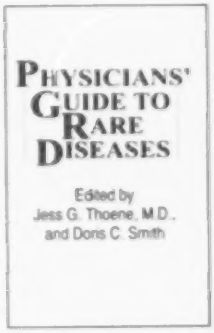


The Woodbine House edition of THE CHILD WHO NEVER GREW brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation. New material written especially for this edition, amplifies her story and gives the book an important historical perspective. This landmark book urges society forward toward greater awareness of people with mental retardation.

DISABILITY AND THE FAMILY — A GUIDE TO DECISIONS FOR ADULTHOOD
by H. Rutherford Turnbull, III, LL.B., LL.M., Ann P. Turnbull, Ed.D., G. J. Bronicki, M.A., J. Summers, Ph.D., & Constance Roeder-Gordon, B.A.
(PB054OD) 432 pp. $29.00

This practical, easy-to-use guide helps answer families questions concerning the future needs of their family members with disabilities. It presents a plan that respects individual choices and takes into account the available social, leisure, residential, and vocational options.

PHYSICIANS' GUIDE TO RARE DISEASES
Edited by Jess G. Thoene, M.D., and Doris C. Smith in collaboration with the National Organization for Rare Disorders.
(DP021OD) $72.50 (plus $6.50 s&h)

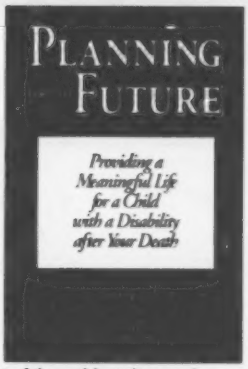


Over 1,000 pgs. contain information on approximately 700 disorders. To assist physicians and others who encounter rare diseases infrequently. It provides ready access to signs and symptoms for differential diagnosis, availability of therapy and a detailed index of symptoms and key words.

To order, use the order form on page 80, or call *1-800-535-1910*

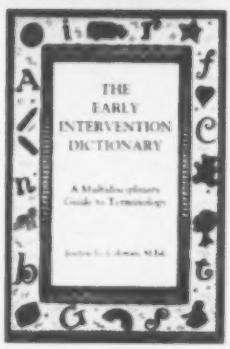
EXCEPTIONAL PARENT LIBRARY

PLANNING FOR THE FUTURE
by Mark Russell
(AP024OD) $24.95



A comprehensive guide for parents of children with disabilities. The 400 pg. softcover publication provides all the info. parents must consider as they plan for their child's life after their own deaths. A comprehensive, authoritative treatment of the subject, it contains twelve chapters and three appendices designed to give all the information parents need to ensure a happy and meaningful life for their children after they die. It draws on the authors' extensive personal experience in planning for families with children who have disabilities.
L. Mark Russell, a co-author, is an attorney and is one of the nation's leading authorities on life and estate planning for families who have a child with a disability. Mr. Russell's earlier book, Alternatives, published in 1983, has been considered a definitive resource on this subject.

THE EARLY INTERVENTION DICTIONARY A MULTI-DISCIPLINARY GUIDE TO TERMINOLOGY
by Jeanine Coleman, M.Ed.
(WB030EI) $16.95



THE EARLY INTERVENTION DICTIONARY defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services. Entries are alphabetized, and include the most frequently used terms in the areas pediatric medicine, early childhood education, OT, PT, audiology, counseling, social work, and more. A great resource for parents.

EXCEPTIONAL PARENT LIBRARY

Mail to: Dept. EP9401, P.O. Box 8045, Brick, N.J. 08723

or call (800) 535-1910

Name

Address

City State Zip

Telephone

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ Visa
☐ Mastercard ☐☐☐☐-☐☐☐☐-☐☐☐☐-☐☐☐☐

Exp. Date Signature

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES	
U.S. – $3.50 for 1 item; 75¢ for each additional item.	Sub-Total
Foreign – $6.50 for 1 item; 75¢ for each additional item.	NJ Residence 6% Sales Tax
	Shipping
	TOTAL

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas

N/D'93

"Our son was misdiagnosed for more than two years. You cannot imagine the nightmare we lived through. The professionals we saw could not identify his illness. We spent huge sums searching for an answer. When his disorder was finally diagnosed, physicians knew little about it."

That all-too-familiar complaint is now being addressed in a 1,200-page, authoritative reference book:

PHYSICIANS' GUIDE TO RARE DISEASES

The book features close to 700 cross-referenced diagnoses, along with easy-to-use indexing. You'll also find standard and investigational treatments, plus further resources, such as associations and support groups.

"Physicians' Guide to Rare Diseases" is based on the work of the National Organization for Rare Disorders and edited by Jess G. Thoene, M.D., president of that organization.

A portion of the book's proceeds is returned to the National Organization for Rare Disorders.

Yes! Please enter my order for
PHYSICIANS' GUIDE TO RARE DISEASES

Name *(please print)* _____

Street address _____

_____

City _____ State _____ Zip _____

Telephone number ( ) _____

☐ Check enclosed *(payable to Exceptional Parent)*
☐ Bill me
☐ Credit card payment: ☐ Visa ☐ MasterCard

Card # _____ Exp. Date _____

PRICE PER BOOK		SHIPPING AND HANDLING PER BOOK	
Single copy	$72.50	U.S. & territories	$6.50
		Foreign	$11.50

Number of books _____
Price each _____
SUBTOTAL _____
Sales tax (NJ residents add 6%) _____
Shipping and handling _____
TOTAL $_____

Mail to:
EXCEPTIONAL PARENT
PO Box 8045, Brick, NJ 08723

Telephone orders welcome.
Please (800) 535-1910

A Service Program for Children, Parents, Hearing Specialists & Educators:

If you like more information on the Oticon 4 Kids program and how it supports children with communicative disorders, call 1 800 227 5021 ext. 555 or write: Oticon, Inc., 29 Schoolhouse Rd. Somerset, NJ 08873.

Rover *all Over*

© 1993 BISSELL Healthcare Corporation J1786

It's...The Carrie Rover from Tumble Forms —offering everything you want in a seat and stroller

Now your special needs child can easily roll from one activity to another. The Carrie Rover can take your child from the home to the car, to strolling on outdoor terrain.

Your child will have freedom and mobility without sacrificing therapeutic support. The anti-thrust seat stabilizes the pelvis while the seat back articulates 20° to accommodate abnormal trunk tone. The Carrie Seat removes for use as a positioning chair and the streamlined roller base folds small enough to fit easily into the trunk of your car.

Lightweight and versatile, Carrie Rover comes in four sizes, pre-school, elementary, junior and **small adult**.

The Carrie Seat has been dynamically crash-tested for use in the car. It complies with F.M. V.S.S. 213. Carrie Rover has been dynamically crash-tested for use on school buses with standard forward facing tie down systems.

Carrie Rover goes anywhere your child wants to...indoors or outdoors.

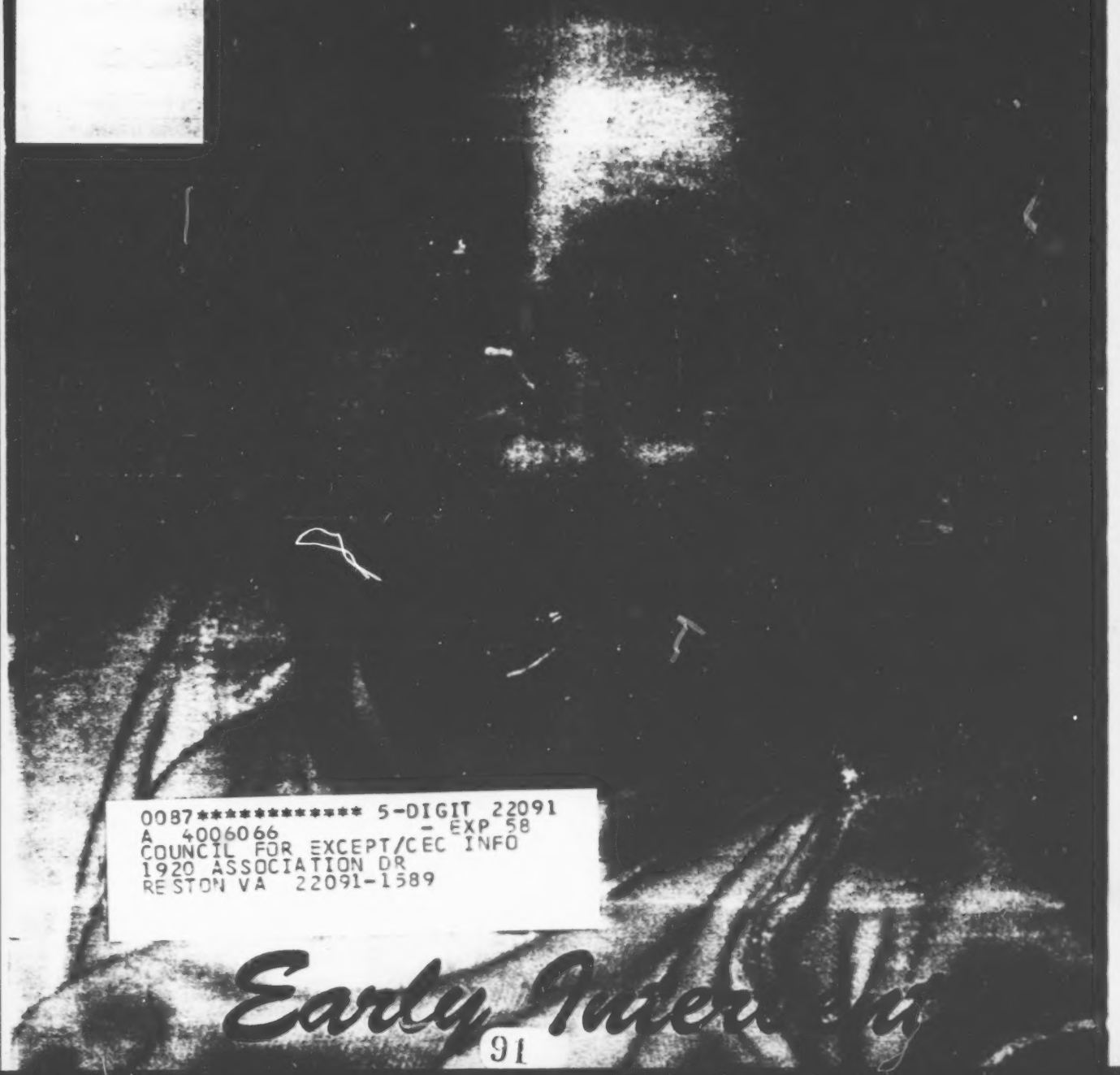
The Carrie Rover—only from Tumble Forms. For more information call 1-800-631-7277 or write to J.A. Preston, P.O. Box 89, Jackson, MI 49204-0089.

Tumble Forms® by **Preston.**

Circle #7

FEBRUARY 1994

EXCEPTIONAL PARENT



0087********** 5-DIGIT 22091
A 4006066 - EXP 58
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1589

Early Inter...

91

NEW!

FOR CHILDREN FROM
20 TO 105 LBS.

© 1993 All Rights Reserved Snug Seat®, Inc.

Let Our **GORILLA** Carry Your Most Valuable Possession!

We named our new car seat the GORILLA because it's stronger than any child restraint device on the market. The GORILLA provides comfort and support for children from 20 to 105 lbs.

The GORILLA's unique fully adjustable headrest provides stable head support, and our innovative pad system and seat extension kit enable the seating area to incrementally grow from 8" x 8" to 14" x 14", ensuring many years of use. The GORILLA also fits into our ROADRUNNER Mobility Base.

1-800-336-7684
Fax 1-704-847-9577
In Canada 1-800-667-3422

THE GORILLA Seat.
BY SNUG SEAT

By SNUG SEAT®, INC. Providing Technologies For Mobility, Positioning & Transportation Since 1987

Federal Motor Vehicle Safety Standard #213 is the U.S. standard governing child restraint devices for children weighing less than 50 lbs. The GORILLA was crash tested with a 105 lb. dummy to ensure shell integrity and test forward head excursion. The GORILLA remained fully intact and forward head excursion was less than even the strict Canadian standard for children under 50 lbs. We highly recommend that you obtain crash test results for any child restraint you consider purchasing. Call us toll free at (800) 336-SNUG for a copy of our results.

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

February 1994 Volume 24 Issue 2

Page 18

Page 30

DEPARTMENTS

2 Editor's Desk
4 Letters
7 Family Support
28 Fathers' Voices
30 Role Models
41 Informational Forum: Networking
53 Research
59 What's Happening
61 Children's Page

FEATURES

18 Early Intervention—A National Overview
by Pascal Trohanis
Charting the development and progress of early intervention programs.

21 Early Intervention Directory
A state-by-state listing of early intervention contact persons.

23 Perspectives on Early Intervention
by Christel Dawkins, Mona Freedman, Cassie Johnston & Judie Walker
Four parent-professionals share their views.

25 A Graduation for Two *by Teresa M. Rafferty*
A mother finds that early intervention is not only for the kids.

33 Editorial Report: Health Care Reform
A look at President Clinton's heath care reform plan and how it may affect your family.

35 Action Alert
How to make your voice heard in the health care debate.

36 Riding the Health Care Roller Coaster
by Larry Allen
A family recounts their bumpy ride.

39 The Helmet *by Joni Pelta*
Mike's mother holds onto her sense of humor.

45 Purchasing Seating Equipment: Tips for Parents/Seating Directory
What to look for when considering a seating system.

55 Annual Income Tax Guide *by L. Mark Russell*
Our yearly journey through the income tax wilderness.

Cover: Eight-month-old Jacob Wilkins of Menlo Park, CA enjoys a bright moment. Now 13 months old, Jacob, who has cerebral palsy, is enrolled in an early intervention program at the Community Association for the Retarded of Palo Alto, where he receives therapy, sings and swims.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly, 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005.

All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation.

POSTMASTER: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Canada, add $6 per year in U.S. funds for additional postage. Latin America and other foreign countries add $9 per year in U.S. funds for additional postage. **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

EDITOR'S DESK

Stanley D. Klein Ph.D.

Over the past 20 years, Congress has passed major legislation to improve opportunities for children and adults with disabilities and their families. Early intervention services were first included in legislation passed in 1986. To provide a context for understanding available programs, Pascal Trohanis ("Early Intervention—A National Overview") offers a broad perspective on the history and current implementation of specific federal regulations. "Perspectives on Early Intervention" presents the early intervention experiences of four parents—Christel Dawkins, Mona Freedman, Cassie Johnston and Judie Walker. In "A Graduation for Two," Teresa M. Rafferty shares some reflections on her daughter's, and her own "graduation" from early intervention.

As members of Congress return to Washington, health care reform is on the agenda. In our editorial report, we discuss some specific concerns of the disability community within the context of the significant positive reforms proposed by the President. We also present the all-too-common story of a family's struggle to deal with their children's staggering health care bills. We urge all of our readers—and their children—to get involved in the reform process.

Last summer, we announced that President Clinton had nominated Judith E. Heumann for the key leadership role of Assistant Secretary for Education and Rehabilitative Services. In this issue, an interview with Judy launches our new regular department, "Role Models." We are delighted to give parents and children a chance to get to know this talented, energetic leader who was once excluded from her local elementary school because she was considered a "fire hazard." We also thank Ilse Heumann, Judy's mom, for sharing some wonderful family photos.

Income taxes are an annual concern. In our "Annual Income Tax Guide," attorney and author L. Mark Russell provides practical information for parents of children with disabilities or chronic illnesses.

Many readers felt a kinship with the parents in the film *Lorenzo's Oil* as they struggled to convince health professionals to recognize the treatment they had devised for their seriously ill child. A few months ago, the national media reported that "Lorenzo's Oil" had been tested and did not work. This month's Research page, however, presents a more complete and balanced report.

More News

Recent issues of *U.S. News & World Report* have included two articles for our readers' "required reading" lists. The cover story of December 13, 1993, "Separate and Unequal: How special education programs are cheating our children and costing taxpayers billions each year," is an important critique. "The Mothers of Invention: How a mighty grass-roots movement of parents with disabled kids is changing the nation" (January 10, 1994) is an inspiring story of dedication. Both articles feature parents whose stories have been in *Exceptional Parent*.

I am honored to announce that four terrific individuals have agreed to serve on our editorial advisory board: Stanley Greenspan, David Hersh, Steven Perlman and Peggy Mann Rinehart.

I am meeting many parents of children with disabilities who are active participants in professional education—educating physicians, teachers, and therapists about the lives of their families. I am also meeting a number of professionals who are interested in increasing the role of parents in professional education. I would like to hear from both parents and professionals about their involvement in such programs.

Many thanks to the hundreds of readers who returned the surveys we sent out to a sample of subscribers. The 40 percent return rate demonstrates that our readers are truly exceptional!

Special Renewal Offer

Our transformation to a monthly magazine has caused confusion for some readers as well as for our subscription office. To end the confusion and reward our loyal readers, every reader will receive a special renewal offer very soon. Please watch for it!

–S.K.

EXCEPTIONAL PARENT

Editor in Chief
Stanley D. Klein, Ph.D.
Professor of Psychology,
New England
College of Optometry

Assistant Editor
Kim Schive

Editorial Staff
Andrew M. Bissaro
Valerie Steele

Editorial Interns
Simone Albeck
Zlati Meyer
Annabel Tan

Consulting Editor
Maxwell J. Schleifer, Ph.D.

Editorial Office
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

President and Publisher
Joseph M. Valenzano, Jr.

Vice President, Marketing
Terri M. Sutera

Vice President, Sales
Kerry J. Cannon

Circulation Manager
Kimberly Tuzik

Director, Organizational Relationships
R.K. Hopkins, Jr.

Vice President, Manufacturing & Distribution
Lawrence Qualiano

Finance Manager
Roy Whitaker

Publishing Office
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240

Art Director
Charles A. Horn

Assistant Art Directors
Donna R. Hunter
Frank N. Avellino

Creative and Production
Morris/Weber & Associates, Inc.
Clifton, NJ 07011

Color Separation/Film Preparation
Plate Masters Inc.
Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 48

BPA International Consumer Magazine
Membership Applied for August 1993

During a 3 year period, children grow an average of 2" in femur length, 1.5" in hip width, and 2.5" in back height.

— extrapolated from *Human Dimensions and Interior Space*

The revolutionary Jay® GS Growth and Positioning System is designed to grow that much and more.

The system includes a new growth Cushion, a new growth Back, and the Jay® Adjustable Solid Seat. Together, these components help position the child's hips and back properly at every step of the growth process. The system is also designed to reduce spasticity and tone.

Call for a free demonstration so that you too can see what a difference a Jay makes!

▲ The Jay GS Growth & Positioning System

JAY MEDICAL

Jay Medical, Ltd.
P.O. Box 18656
Boulder, Colorado
80308-8656 USA
(303) 442-3529

Toll-free
(800) 648-8282

In Canada, call
(800) 263-3360

© 1992 Jay Medical, Ltd.

Circle #44

LETTERS

Letters to the Editor

A Fine Purpose

After an extremely long ISP (Individual Service Plan) meeting, I fell into bed exhausted, but was revived by reading Carol Abbott's article, "A Fine Purpose" (October 1993).

I want to thank her for sharing their lives and the life of their son Brian in such a warm and articulate way. The article is such a wonderful tribute, not only to Brian, but also to the many other wonderful children with severe physical, mental and medical disabilities. It reminds me again of the value of each life, that wonderful "beingness" of each God-given person. I was truly blessed.

S.B.
Washington

■ I was very encouraged by Carol Abbott's story about her son Brian. I was deeply moved to read of Brian's life and of Carol's search for answers as to why this "tragedy" had befallen her family.

I believe all of us who have been touched by a child with a disability, believers in a higher being or not, come to question God as to His purposes. For some, when the questions appear unanswered, faith in God wanes and life goes on without Him. How very sad. For others who will not be satisfied without an answer, the answer inevitably comes.

Thank you for printing Carol's article in *Exceptional Parent*. I have been a subscriber for almost a year and have until now been disappointed by the absence of faith-inspiring material. While I realize this is not a "religious" magazine, many of us hurting parents believe deeply in God and His grace and depend on Him daily. Thank you for helping to meet a need of mine.

N.J.S.
New York

■ Just a short note to let you know that I very much enjoyed the article, "A Fine Purpose." Ms. Carol Abbott really wrote this article with her heart. A special thanks to her for being able to write down so well what I feel myself.

L.L.
Ontario, Canada

Liberty and Choices

Thank you for your editorial, "Liberty and Choices for All" (June 1993). The fervor with which the proponents of inclusion promote their belief is disconcerting. It is fine to have strong beliefs, but it is just plain uncomfortable to read documents that imply that to value any other model is wrong.

Thoughtful parents, thoughtful educators and thoughtful advocates recognize that the beauty of our country lies in choice. A continuum of services for children with disabilities—from residential to full inclusion—gives each of us the power to make our own decisions. Let's respect this gift. Your editorial states the need for respect well. It is appreciated.

V.A.D.
Oregon

Parent-Teacher Cooperation

Thank you for the articles, "Parent-Teacher Cooperation: A Shared Responsibility" and "Effective Parent Advocacy: How to Take Charge" (September 1993). They contained valuable information. I had to laugh over the statement, "Visit your child's classroom to see how she spends a typical day. Parents are always welcome." That is not true at all schools! The school

P.F. Responds—It's not about labels!

In the April/May issue of *Exceptional Parent*, the headline "Documentary About Learning Disability Wins Academy Award" appeared above a news item about the film *Educating Peter*, the story of a student with Down syndrome.

In the July/August issue, *Exceptional Parent* printed my letter expressing distress at the headline's implication that a film about Down syndrome is a film about learning disabilities. Five letters in the October and November/December issues expressed offense at what I wrote.

I'm sorry. My quarrel was never with those parents or their children! My quarrel was with *Exceptional Parent* and its editors. They know the difference between learning disability and mental retardation, but let a carelessly worded headline slip by them.

I am not guilty of the insensitivity and ignorance of which those letters to the editor accuse me. Apparently, however, I *am* guilty of poorly expressing a point I still believe must be made. I desperately hope that this time I can make my point without offending anyone.

It may help to know that we had three sons. My own beloved firstborn son had a mucopolysaccharidosis—a progressive degenerative disease. He was big, well and bright until he was four, but then became gradually dwarfed, ill and retarded until he died at 15. P.B. of Georgia, watching his intelligence fade was heartbreaking, but, like you, we were at least as concerned about medical complications. We loved him so! And though we hoped, there really was no hope.

Our second son is profoundly deaf. He has had a wonderful education, but that was never a foregone conclusion. We fought tooth and toenail to, first, learn what *we* should do so that he would be able to do all *he* could do. Then we worked equally hard to find the programs that would help us do it. That sometimes meant we had to create the programs.

Our third son is the one with learning disabilities (LD). When my children were small, services existed for children with mental retardation. There were proven methods for teaching children with impaired hearing. But learning disabilities were not understood at all. Neither diagnostics nor programs were available. That they exist now (and that some children with Down syndrome benefit from them) is due in part to parents and professionals who have been my friends and support in the Learning Disabilities Association (LDA).

continued on page 44

system we belong to has refused to let mothers observe in a classroom. It makes a parent wonder why.

J.A.
Texas

Diabetes Insipidus—Wrong Advice

You gave M.R.P., Pennsylvania (Parents Search–November/December 1993) the wrong advice by referring her to the Juvenile Diabetes Foundation. Diabetes insipidus has no relation to diabetes mellitus—so-called "juvenile diabetes," but technically referred to as "insulin-dependent diabetes mellitus." Diabetes insipidus is due to a deficiency of anti-diuretic hormone, not insulin.

R.J.K.
Maryland

■ I am the parent of a child with diabetes insipidus. An excellent resource is the newsletter from the Diabetes Insipidus and Related Disorders Network (c/o Beth Perry, Rt. 2 Box 198, Creston, IA 50801, 515-782-7838).

M.C.A.
Maryland

Feedback

I'm writing to tell you how my life has changed so much since I started receiving your magazine a year ago.

My daughter Christine is two years old. She has cerebral palsy, cortical blindness, mental retardation and a seizure disorder. I could never bring myself to even say these diagnoses before. I did nothing but cry, pray, hope and wish things were different. I could not understand why or how this could happen. Day by day, nothing seemed to change. I'd have a doctor's appointment and leave upset. I'd see another baby and cry. I'd think of what she would have or could have been doing and I'd cry. I never gave up on prayers. I always loved and accepted her. It wasn't until later that I knew why God gave her to me.

I started receiving your magazines and reading them over and over. It seemed everyone felt the same way in the beginning. I started to understand more. I felt that God had chosen me and all these other parents.

My friends and family pass the magazine around and it helps all of us understand. We read parts to our older daughter, Theresa, so she knows her sister isn't the only one and that she is special like these children.

Thanks to *Exceptional Parent*, I understand my baby a lot better and I will never give up on her.

C. G.
New Jersey

■ Thank you for a great magazine filled with support over the years. Our son has died, but we will continue to subscribe. We feel that once you have been part of the truly exceptional world of disabled children and their families, you can never forget them and their needs and causes.

Please consider including more articles about the death of these children: how to cope with a terminal child, preparing for death, dealing with siblings and surviving after they are gone. The medical community doesn't always treat the entire family, and they move on to others after a death. We are a special group in need. Thanks!

G.R.
Oregon

■ I have appreciated *Exceptional Parent* over the years. Thanks for working for us parents and for being such an encouragement.

I thought you might like some input from a parent. Since the changes last summer, I feel you've

We welcome all letters from readers—reactions to articles, suggestions, opinions, complaints. Write or fax:
Letters to the Editor
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005.
Fax: (617) 730-8742

At Devereux...
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle #19

become more of a scholarly journal and less of a magazine for an at-home parent. There is much less encouragement from parent to parent.

I am still changing diapers on an eleven-year-old, trying to balance medicines with seizures, preparing meals, doing laundry, coordinating the rest of the family and loving every one of them. Advocating in formal situations is not what I do most. And I'd like to hear from parents who know where I am, because they remember what it was like. Few articles lately have spoken my language.

In the November/December 1993 issue, for instance, the only things of interest to me were Parents Search, Parents Respond, Parenting and Fathers' Voices. The Children's Page used to be good with sibling input. I would often share it with my three "normal" kids, but no longer.

I have been putting off writing this for several months to see if things would change. They didn't, so I am getting things off my chest. I still appreciate the work you're doing. Thanks.

C.O.
Washington

Fathers' Voices

Special thanks for adding a column for fathers, the "forgotten parent." I have had the pleasure of receiving Mr. May's newsletter for the past year. We need more circulation of his materials as you are doing.

Your decision to publish on a monthly basis is an excellent one also, since so many of the issues in which we are involved are fast-moving and need monthly attention.

M.M.
Florida

Search Letters Pay Off

Thanks to *Exceptional Parent*, a nationwide network has been formed for parents with children with insufficient myelinization.

Less than a year ago, we were all in the dark, getting no information from any organization on this disorder. Today, we are united and growing, thanks to your magazine for printing my Parents Search letter. I had such a big response that I started the *Myelin Messenger* newsletter (c/o Ruth Anderson, HC-29, Box 686, Stable Lane, Prescott, AZ 86301-7435).

Now, we are not alone and hopefully, future parents will not be left in the dark. With the advent of magnetic resonance imaging, it is likely many more children will be diagnosed with this disorder.

Your magazine is a wonderful resource for all of us. I look forward to each issue and read it from cover to cover. It's dog-eared when I finish it, but I pass it on to another grateful parent anyway.

R.A.
Arizona

■ I am grateful to everyone who responded to my Parents Search letter on large-size, pull-up style diapers. I have contacted Kimberly-Clark, the company that manufactures Pull-Ups, and they have told me that their research and development department is currently working to develop Pull-Ups in larger sizes.

The more consumer information Kimberly-Clark has, the sooner they will be able to get this product on the market. I have sent them all the letters I received from readers of *Exceptional Parent*. If you have not written yet, or have more information for them, please write to: Kimberly-Clark Corporation, Attn: Consumer Services, P.O. Box 349, Neenah, WI 54957-9953.

Also, in response to suggestions to use non-disposable, pull-up style diapers, most parents will find that school systems will not accept anything but disposable diapers.

G.M.F.
New Jersey

Young Artists Wanted

Exceptional Parent is now using children's artwork to illustrate feature articles and departments. We invite your children to share their work with our readers. Send artwork to:

Exceptional Parent
Children's Art
209 Harvard St., Suite 303
Brookline, MA 02146-5005

Put the picture's title, along with the child's name and address, on the back of submitted artwork.

Editorial Advisory Board

- **LARRY BELFORD**, Director, Marketing Research & Strategic Analysis, Ciba-Geigy Pharmaceuticals, Summit, NJ
- **LISA BLUMBERG**, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
- **T. BERRY BRAZELTON**, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
- **FRANCES P. CONNOR**, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
- **ALLEN C. CROCKER**, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
- **ELI FACTOR**, D.M.D., President, Wheelchair Motorcycle Association, Brockton, MA
- **MURRAY FEINGOLD**, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
- **SANDRA B. FLEISHMAN**, Parent and Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
- **BRUCE M. GANS**, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
- **SOL GORDON**, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
- **STANLEY I. GREENSPAN**, M.D., Clinical Professor of Psychiatry and Behavioral and Pediatrics, George Washington University Medical School, Washington, DC
- **HERBERT J. GROSSMAN**, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
- **DAVID HIRSCH**, M.D., Phoenix Pediatrics, Phoenix, AR
- **GOODWIN D. KATZEN**, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
- **SUSAN M. KLEIN**, Ph.D., Professor of Special Education, Department of Education, Indiana University, Bloomington, IN
- **EDWIN W. MARTIN**, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
- **JAMES MAY**, M.A., M.Ed., Project Director of the National Fathers' Network, Bellevue, WA
- **JEAN B. McGREW**, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
- **EDWARD NEWMAN**, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
- **BETTY PENDLER**, M.S., Member, New York State Developmental Disabilities Planning Council, New York, NY
- **STEVEN P. PERLMAN**, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
- **HARVEY PRESSMAN**, President, Corporation for Opportunity Expansion, Newton, MA
- **SIEGFRIED M. PUESCHEL**, M.D., Ph.D., M.P.H., Dir., Child Dev. Ctr., Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
- **PEGGY MANN RINEHART**, B.A., Parent and Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
- **JEROME ROSNER**, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
- **HARILYN ROUSSO**, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
- **BARBARA J. SEABURY**, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
- **HOWARD SHANE**, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
- **CAROL TINGEY**, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
- **HAROLD TURNER**, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
- **IRVING KENNETH ZOLA**, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

Parents Search

Sibling Seeks Pen Pal

I am an 11-year-old girl who has a brother with autism. I would like a pen pal who has a sibling with a disability.

J.A.
Texas

Coping with Uncontrollable Seizures

My friend has a 21-year-old son with partial complex seizure disorder uncontrollable by medication. He has had several brain scans and is currently undergoing diagnostics to see if he is a candidate for surgery. Possible surgical procedures are subdural electrode implants and epidural pegs.

Matt is learning to live with his epilepsy and is living independently for the first time, but is still unable to work and drive. His best friend is in college on the East Coast and he feels all alone. He feels like he is the only person in this situation. He is in dire straits emotionally. Please contact us if you know of anyone else in this or a similar situation.

M.M.
Michigan

LD—Resources for Dealing with the System

I am the mother of a nine-year-old boy with several significant learning disabilities. I am interested in corresponding with other parents who are facing (or who have solved) the same kinds of challenges. Could you please help me find some parent resources to deal with the educational system and the learning process?

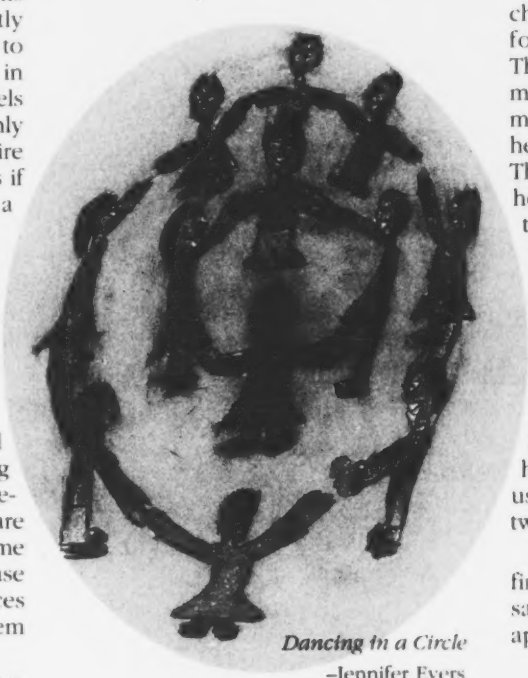
K.R.
California

College with a Personal Attendant?

I am the parent of a 15-year-old daughter who has cerebral palsy. She uses a motorized wheelchair and is unable to dress, bathe or transfer out of her wheelchair by herself. She will always need an attendant to help her. She also has difficulty writing, and gets frustrated using her computer because she is a one-finger typist.

My daughter is an honor student and wants to attend college. Either my husband or myself must help her with her homework now—we do all the writing—but we will be unable to do this for her when she's attending college. I would like to hear from anyone who has had experience with a person unable to write who was able to attend college. How did they complete written assignments? I also would like any information on colleges for a person who would need attendant care.

N.T.
New York



Dancing in a Circle
–Jennifer Evers
Cotting School, Lexington, MA

Service Dogs

My eight-year-old son has spastic diplegia cerebral palsy. He is ambulatory but has poor balance. He desperately wants a dog.

A while ago, I saw a television show about service dogs for people with disabilities. These dogs were trained specifically for the problems of their owners-to-be. Does anyone know how I can contact this type of trainer/kennel? I'd appreciate any information!

J.M.W.
New York

Transporting Two Non-ambulatory Children

I am the mother of three boys, two of whom have multiple disabilities and are non-ambulatory. Nick is five years old, and can sit independently for short periods of time. Chris is almost two years old and is *very* close to sitting independently. I am in search of a way to transport both boys single-handedly.

Nick has a custom-fitted wheelchair that works well. Chris is comfortable in a stroller at this point. There are many places that I can take my children, but I can never go by myself. I always need someone to help push a stroller or a wheelchair. The difference in the boys' ages and heights creates a problem. If something works well for one, it doesn't work well for the other.

My ideal form of transportation would be something that is easily transportable by folding to fit in the trunk of a car or the back of a van. It should be adjustable to fit the growth of my sons. Also, if possible, it should be something that can be hooked together for a single person's use, but can also be taken apart for two people to use.

If anyone has any suggestions in finding a long-lasting, affordable and safe form of transportation, I would appreciate your help.

D.H.
Ohio

Ideas for PTO Activities

My five-year-old son is in his fourth year in a preschool program for kids with special needs. We have a parent-teacher organization that meets monthly. Sometimes, we have speakers or a family activity or talk about fundraising. The participation is very poor. I would like to hear from other parents about their school groups.

What activities do you do, how do you get parents interested and has your group accomplished any great feats that you are proud of?

R.N.
Virginia

Tenth Chromosome Inversion

We have two lovely daughters—Shelby, twenty-three months and Rebecca, three months. Both girls have an inverted tenth chromosome. Geneticists have told us that this inversion is not known to cause birth defects. (My husband has this inversion and there is no familial history on either side of any birth defects.) In fact, after the birth of our first daughter, they told us that there was little if any chance of a recurrence. They were as shocked as we were when our second daughter showed up with almost identical problems.

Shelby had a small ventricular septal defect and patent ductus arteriosus not requiring surgery, a major esophageal reflux requiring G-tube placement, hydronephrosis on the left and a non-functional kidney on the right with major ureteral reflux requiring corrective surgery. She also has developmental delays. Her younger sister had coarctation of the right aortic branch, a small ventricular septal defect and similar problems with her stomach and kidneys.

Of course, we would like to know why. But most of all, we would like to know we are not alone.

P.U.
Pennsylvania

Riding the School Bus

Our son is seven years old and mildly autistic. During the four years he has been in school, either his dad, the baby-sitter or I have driven him to school. Our family has found this to be a very satisfactory arrangement. Almost every one of our son's teachers, however, has urged us to have our son ride the school bus instead. They say they believe *very* strongly that riding the school bus is an important part of going to school. Is there any research that supports the idea that riding the school bus is better than having a family member drive the child in a car? Are the teachers likely to prefer the bus for reasons they are not discussing?

N.S.
New York

Haverich

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

ORTHOPAEDIC CYCLES

Circle #36

100

Three Kids, Three Disabilities

I'm the parent of three beautiful children who bring my husband and I great joy and happiness. But we are upset that all three have totally different impairments. Brian is three-and-a-half years old. He doesn't have a diagnosis except developmental delays, sensory integration dysfunction and "slow-to-warm-up" syndrome. He also has asthma. He is still unable to dress or undress himself, is not toilet-trained and cannot ride a tricycle or catch a ball. Cognitively, he is either normal or above average for his age.

Joshua is 19 months old. He has septo-optic dysplasia, oculocutaneous albinism and a hypoplastic left kidney with reflux. He is also hypoglycemic. I've been searching for a long time for any family who may have a child with both septo-optic dysplasia and albinism. Josh is the first that our geneticists are aware of. Developmentally, Josh is right on target, except for things that require vision, because he is legally blind.

Corey is two months old. He was born with a rare heart defect, hypoplastic right heart syndrome. His prognosis is uncertain, so we consider each day he's with us a gift. He underwent open-heart surgery immediately after birth and faces two more surgeries by his first birthday. It's not a cure but a band-aid. He also appears to have optic nerve hypoplasia or optic nerve atrophy.

We have had *extensive* genetic counseling and no one can determine

Family Support, including **Parents Search** and **Respond**, is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published in **Parents Respond.**

Write or fax:
Parents Search or **Parents Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 6923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994)

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine

- ❑ One Year (12 issues) for $24.*
- ❑ 3 Years (36 issues) for $54.* **BEST BUY!**

*US funds only. Canada add an additional $6 per year for postage. Other Foreign countries add an additional $9 per year for postage.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 34B

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine

- ❑ One Year (12 issues) for $24.*
- ❑ 3 Years (36 issues) for $54.* **BEST BUY!**

*US funds only. Canada add an additional $6 per year for postage. Other Foreign countries add an additional $9 per year for postage.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 34B

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

See reverse side for subscription details

why our children all have impairments, and why all three children have something different. I would like to hear from anyone who might be able to give us some insight. I would also like to hear from anyone who is in a similar situation—how they cope emotionally, how they find time for themselves, how they find time to be just a "normal mom" instead of always dealing with doctors, therapists and bills.

P.G., Pennsylvania

PDD/Autism and Muscular Dystrophy

Our six-and-a-half-year-old son was diagnosed at 15 months with pervasive developmental delay/autism. At three, we learned he also has Duchenne muscular dystrophy. The specialists who deal with our son have no other patients with this dual diagnosis. We are interested in hearing from parents of children with the same diagnosis to compare notes and perhaps shed some light on our special children.

J.M.F.
Massachusetts

Trisomy 19Q

Our son is four-and-a-half years old and has Trisomy 19Q. He is the eleventh reported case in genetic history. Jacob's development is significantly delayed. He has Tetralogy of Fallot, severe hypotonia and seizures. He is G-tube fed and considerably underweight. He weighs 22 pounds and is visually impaired, so he wears glasses. Presently, he is on medication for seizures and constipation.

Jacob is making progress in sitting up with assistance and is walking with a Rifton walker. He cannot talk or crawl, but he is a professional roller. He pulls himself forward with his arms, his legs dragging behind. He gets around the house by rolling or scooting on his back. Jacob is a very loving, social, happy child. When he smiles, the world smiles with him.

We have been on a worldwide search for another child Like Jacob. I've written to more than 150 different genetic research centers, national information services, support organizations and medical facilities with no success. We would love to hear from other parents of children like Jacob who have similar problems.

D.L. and R.L.
North Carolina

Rasmussen's Syndrome

My nine-year-old daughter has recently been diagnosed with Rasmussen's Syndrome. She has undergone two craniotomies to stop the motor seizure activity. She is currently using a walker and is on numerous anti-seizure medications. I would appreciate any information from other families who have dealt with this syndrome, as her future prognosis remains uncertain due to the limited number of children with this condition.

S.K.J.
Nebraska

Langer-Giedion Syndrome

Our two-year-old daughter Ariel was born with a deletion in the long arm of her eighth chromosome (8q-[23.3-24.22]). At six weeks of age, she was diagnosed with Langer-Giedion syndrome, also called Trichorhinophalangeal Syndrome Type II. We have been searching without success for another family affected by this very rare syndrome.

Ariel has many of the characteristics that are common to this syndrome: slow-growing, sparse hair; large, low-set ears; bulbous nose; thin lips; multiple skeletal anomalies and short stature. Some additional problems she has which are not usually associated with this syndrome are multiple heart defects, severe feeding difficulties—Ariel is gastrostomy fed—and recurrent episodes of undiagnosed, uncontrollable vomiting that occur every two to three weeks and last two to five days.

Ariel currently scoots on her bottom to get around, but we are confident that she will be walking within the next year. She uses American Sign Language to communicate, as her speech is delayed. Cognitively, Ariel appears to be doing very well. She has an excellent attention span and already knows over 40 signs. Ariel is a very active and social child who charms everyone she meets.

We would very much like to correspond with other parents of children with Langer-Giedion Syndrome and/or undiagnosed episodes of vomiting. We are looking forward to hearing from you!

A.R. and R.R.
Minnesota

Children's laughter is music to our ears.

Our dedicated staff at the Kennedy Krieger Institute is devoted to helping children and adolescents with physical, mental or educational disabilities. Through diagnosis, treatment and education, we can help find the key that unlocks the future for your child and your family.

Kennedy Krieger Institute...providing quality services for youngsters of any age with:

- Assistive Technology Needs
- Motor and Language Delays
- Metabolic & Degenerative Diseases
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

Kennedy Krieger Institute

A comprehensive resource for children with disabilities

Call us to talk about your concerns, slight or severe. We can help.

(410) 550-9400 / 1-800-873-3377
707 North Broadway
Baltimore, MD 21205

Circle #45

Parents Respond

G-Tube

T.G. (October 1993) is the parent of 28-month-old Joseph who was born prematurely and suffered a grade IV brain hemorrhage. Joseph has feeding difficulties and is currently underweight. Though his doctor recommended G-tube placement, T.G. wondered whether this would be beneficial since Joseph also has reflux.

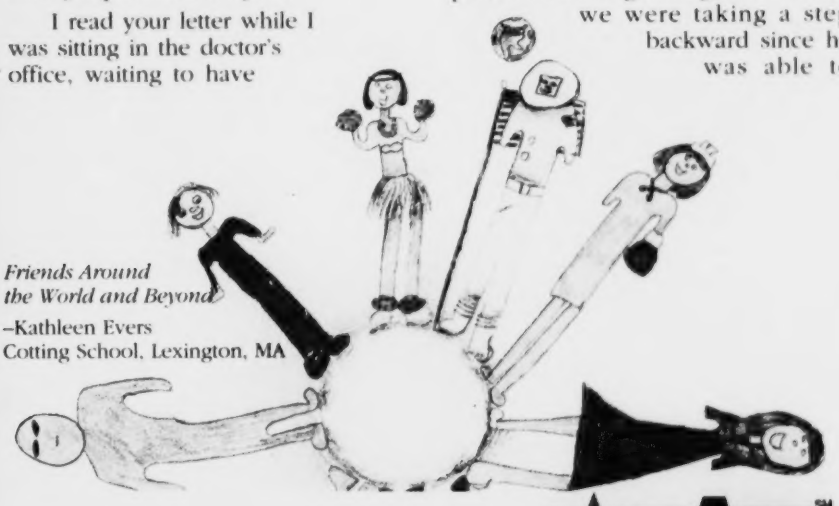
I read your letter while I was sitting in the doctor's office, waiting to have my son's recently placed G-tube checked. Your letter could have been written about my own son, Jake. He was a 32-week preemie who also suffered a grade IV bleed. He is now 31 months old and is unable to hold his head up or do much of anything for himself.

Our decision to have a G-tube placed was an agonizing one. We felt we were taking a step backward since he was able to eat to some extent. However, each of his feedings was taking up so much of our time with such little result. Jake always had a reflux problem, so we shared the same concerns as you. Our coping ability and Jake's tolerance were nearly exhausted.

Our neurologist, pediatrician and gastroenterologist all recommended a G-tube. (Jake was 28 months old and weighed 17 pounds.) A nissen was also performed to prevent any occurrence of reflux or aspiration. This procedure is actually more difficult than the G-tube placement, but well worth it.

Although there were some initial difficulties, now we are so glad that we decided to go ahead with it. Feedings are easier, and Jake has gained weight. Our stress level is down, his comfort level is up, and we feel we are able to spend more quality time with him. It is a slightly difficult transition, but once learned, benefits the entire family. His diet consists of Pediasure with fiber, pear juice and water. His medicines go directly into the tube as well. (Jake has a button and I also recommend you inquire about that.)

R.N.I.
Utah



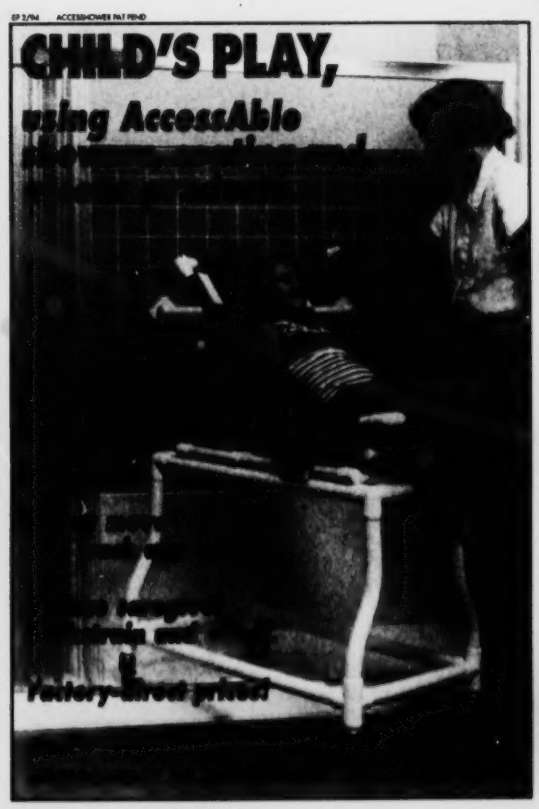
Friends Around the World and Beyond
–Kathleen Evers
Cotting School, Lexington, MA

Puberty and Autism

P.K. (September 1993) is the parent of a nine-year-old girl with autism who is rapidly approaching puberty. P.K. was concerned about how to handle the onset of her daughter's menstruation since she usually removes her clothes during the night.

I'm the parent of a 15-year-old daughter who has mental retardation with some autistic characteristics. My daughter wets during the night. We had a problem with her pulling her disposable briefs off and tearing them up. In the winter, I used a safety pin to hold the zipper up on blanket sleepers. She's very strong, however, so I was afraid she would break the pin and get hurt. Then my mother made her some one-piece pajamas that zipped in the back. They worked great until the summer, when she made them short-sleeved and short in the legs. She used a thin cotton knit material.

When my daughter began menstruation, we had two problems: the



Access
ENVIRONMENTS + PRODUCTS

BARRIER-FREE ACCESSHOWERS™ FOR THE WHOLE FAMILY
- ✔ **Accesshower™** kit with door to replace inaccessible bathtubs
- ✔ **Accesshower™** system with door for the new accessible bathroom
- ✔ **FreeAccess™** accordion-fold or **BeautyAccess™** bi-fold barrier-free showerdoor kits for existing showers
- ✔ **Anywhere, Anytime Accesshower™** for portable, short-term use (MID-'94)

SHOWER, BATH, TOILET SEATING
- ✔ **AdjustEase™** and **ReclinEase™** reclined shower/bath chairs for infants, children, teens and adults
- ✔ **RollEase™** wheeled upright shower-toilet chairs in many sizes/capacities
- ✔ AccessAble chairs have the best easy-roll, no-rust wheels available and also offer many optional adaptive features

SHOWEREASE ACCESS PRODUCTS
- ✔ **SoloAccess Ramp™**, portable, for 1"–3" barriers, 20"L x 30"W, 12 lbs
- ✔ **SitEase™** wall-mounted benches
- ✔ **SafEase™** adjustable grab bars in various sizes and shapes
- ✔ **Accessspray™** adaptive hose showers specially-mounted on sturdy grab bars
- ✔ **TempEase™** anti-scald shower controls

Circle #9

NO RISK!

CALL TO ORDER FREE INFORMATION!
1 800 285 2525

pads were too wide and in the blink of an eye, she would reach into her pants, pull the pad off and throw it. I found that the extra long size with wings solved the width problem. Because of the wings, I could make them very narrow. She now wears bib overalls and one-piece jumpsuits to prevent her from reaching into her pants. She leaves the pad alone and we have no more embarrassing moments.

D.S., Michigan

Wide Shoes

D.M.G. (September 1993) was looking for a source of wide dress shoes for her 30-year-old daughter who has Down syndrome.

Your question wasn't mundane. Finding wide shoes in an age-appropriate style is difficult. My 16-year-old daughter wants "in" shoes, but braces make them hard to find. We've found wide shoes in the Massey's shoe catalog, P.O. Box 10088, Lynchburg, VA 24506-0088. The selections are limited in size four, but there are a few. Good luck!

No name or address given

Parents with Disabilities

C.L.B. (November/December 1993) has a neuro-muscular disease, and is also the parent of two preschoolers, one of whom is a four-year-old boy with autism. Her situation has become even more difficult since her husband passed away last spring. She wondered how other parents with physical disabilities coped with everyday problems.

I have been a subscriber to *Exceptional Parent* since shortly after my daughter was born in July, 1991. So many letters and articles in *Exceptional Parent* have touched me, but none more than yours since I am also a disabled parent of a child with a disability.

My daughter has Larsen's syndrome, a rare congenital disorder involving multiple joint dislocation, characteristic facial features and in Emily's case, a potentially serious instability of the cervical spine. Although Larsen's is considered rare, her case was immediately diagnosed since she inherited it from me, her mother. All the genetic counseling I received prior to my marriage indicated that there was virtually no risk of my bearing an affected child. Now, the risk is known to be 50-50 and this weighs heavily on my mind when considering more children.

In your letter, you asked how disabled parents cope with everyday problems. First, I realized that I have no choice but to cope. She is my daughter and I love her with all my heart.

Next, we organize our surroundings to make my life easier. It may sound simplistic, but I have found that comfortable, supportive furniture eases the back pain I suffer due to my dislocated hips. In our former apartment, we also had diaper-changing tables both upstairs and downstairs. Recently, we moved to a one-level apartment since Emily is not likely to handle stairs for some time to come. She can now walk with a walker, but there are still many occasions when I must lift and/or carry her! My husband does all the heavy housework and assists with most household chores.

I realize, however, that you are a widow. Do you have the financial resources to employ a housekeeper or home health aide? If not, do you have insurance which might cover such services for you, based on your condition? Or do you have other family or friends that would be willing to help out with everyday activities?

Life Planning Should Be A Team Effort

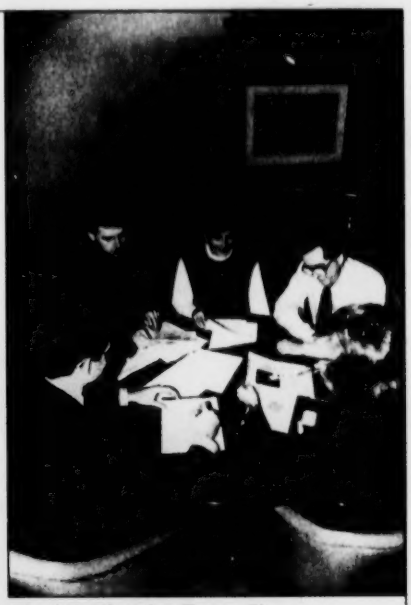
Providing for the future needs of a family member with a disability can be a complicated matter. Families often need the help of those with specific knowledge and experience to be certain they are making the best choices for their loved one.

Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidelines to hundreds of families every month. Our national network of skilled and experienced local attorneys and estate planners can assist families with a son or daughter who has a disability to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD representatives provide FREE initial interviews to determine your needs and FREE group seminars for parents. We have an office near you. EPPD is not a guardianship or master trust plan, but assists parents in locating the services necessary to provide a secure future for their loved one.

Call today to receive a FREE brochure and the location of your local EPPD representative.

800-448-1071

Richard W. Fee, Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303



The Life Planning Team: *The person with a disability, family members, attorney and EPPD Representative.*

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

Circle #26

Amanda could hardly contain herself as they set her chair into the wheelchair swing...it seemed like she'd been waiting for this for a hundred years. She gripped the swing tightly between her fingers, took a deep breath and said, "I'm ready!" Then, as they put the swing into motion, her hesitant smile became an ear-to-ear grin. For the very first time in her eight-year-old life, Amanda was swinging.

For Amanda and others like her, our special seven-week summer program is a place where children with multiple disabilities, ages 5-21, can discover the joys of achievement.

The opportunity to make new friends...learn new skills...and increase independence awaits! We combine functional academics in special education classrooms, lifeskills in home-like environments, individualized therapies, exciting leisure/recreation activities in community-based settings and caring, professional staff members for a summer full of smiles.

Enroll Now For Summer '94!

Summer Session: June 20 - August 5
Application Deadline: April 1, 1994

HEARTSPRING™

A LIFESKILLS LEARNING CENTER

2400 JARDINE DRIVE
WICHITA · KANSAS 67219-4699
800 · 835 · 1043

Circle #38

I realize that these suggestions aren't original. No one more than me understands the physical and emotional pain of disability. Just remember that somehow we will always manage to get through the rough times, because we have to do it for our kids.

E.L.K.
New York

Semilobar Holoprosencephaly

M.M.R. (November/December 1993) is the parent of a ten-month-old daughter, Chloë who has been diagnosed with Semilobar Holoprosencephaly. Chloë was given a bleak diagnosis, but is now doing quite well. M.M.R. wondered about her true potential.

I have a four-year-old daughter with Semilobar Holoprosencephaly and Hydrocephalus. Dara's original pediatric neurologist suggested that we not consider any habilitative programs since her life expectancy was short. We also were given a very bleak prognosis.

Four years later, she has made remarkable progress. Dara now can crawl around anywhere. She can use a walker for short periods of time. She speaks in single words and can name many items. Her vocabulary consists of approximately one hundred words. She just learned to count to ten. She loves sing-along videos and books.

Dara is enrolled in the three-to five-year-old program in our public school. It is unbelievable how much difference the stimulation, learning and other children have made in her life.

I encourage you to take Chloë to appropriate therapies. I cannot say enough about how speech, occupational and physical therapies have helped Dara. The knowledge, support and friends I've gained through taking her to her therapies has also helped me.

As I have been typing this letter in my office, Dara has been playing on the floor, "reading" papers from the trash, trying to pound on my keyboard and singing the ABC's.

J.S., Illinois

Cochlear Implants

C.N. (October 1993) asked about the pros and cons of cochlear implants for children with multiple disabilities in addition to profound deafness.

I am a parent of a two-and-a-half-year-old child with multiple disabilities

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford Ford and Lincoln-Mercury Divisions

Circle #30

who has a cochlear implant. Daniel suffered an infection of staph pneumo meningitis last year that left him physically devastated. His current condition includes developmental delay, hydrocephalus with ventriculoperitoneal shunt, seizure disorder, left third-nerve palsy with ptosis, gastrostomy button and profound bilateral sensorineural hearing loss.

For our family, the cochlear implant was like a miracle. Before the implant, Daniel had no interest in the external environment. He found no toy worth reaching for and he was not motivated to move his body. He even seemed to ignore us. Just two days after being fitted with his processor, he was *reaching* for those very same toys, because *he could hear* them. When I spoke, he put his hand on my mouth. From that point on, Daniel has made rapid, improvement in all areas, not just those related to hearing.

Daniel now wears his processor during all his waking hours. He smiles when we fingerspell "C-I" before we put it on, and really seems to enjoy hearing. He laughs at silly songs and enjoys the Muppets on *Sesame Street*. I've even seen him turn his head to find the singing birds. He responds to his name spoken from several feet away. Our audiologist feels he will probably end up with a moderate hearing loss (40–45 dB). All I know is that my profoundly deaf son can hear!

I strongly encourage you to find a cochlear implant clinic and see if your son is a candidate. Some children cannot be implanted because of anatomical malformations or the presence of residual hearing. Not all clinics will perform the implant on a child with multiple disabilities. You may have to travel a great distance.

S.A.
Iowa

EME and Nonoxynol-9 Spermicide

M.D. (October 1993) is the parent of five-and-a-half-month-old Austin who has been diagnosed with Early Myoclonic Encephalopathy Syndrome (EME). Austin was conceived while his parents were using the contraceptive sponge with Nonoxynol-9 spermicide. M.D. was looking for other parents of children with EME, and also wondered if other parents of children with disabilities had used Nonoxynol-9 at conception or during pregnancy.

It was amazing to me how familiar your situation sounded. Our 22-month-old son, Scott, has been diagnosed as having cerebral palsy and a multiple seizure disorder. Two of the types of seizures he has are called myoclonic and tonic-clonic seizures. He also suffers from startle reflex and constant muscle spasms. Until recently, his seizures have always been very difficult to control—at one point, he was having seizures every 10 minutes. Scott is severely developmentally delayed. He has very little head and body control, and like Austin, is cortically blind.

Most interesting to me is that Scott was also conceived while we were using a contraceptive sponge with Nonoxynol-9 spermicide. We had two completely healthy children before Scott was born. Our second child was only five months old. We planned no other children, so like you, we had no reason to believe I was pregnant. I would be very interested to know if you find other parents with the same or similar circumstances.

S.H.
Alabama

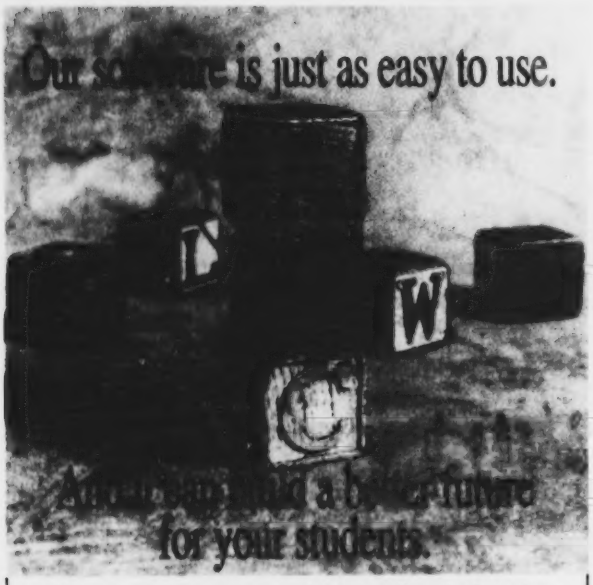
Take a
Firm
Position!
Three models, three colors, rugged durable, lightweight, more than twenty positioning features, three year warranty

"Convaid Cruisers" . . . firm positioning buggies for children with special needs.

Your child's comfort is assured by the care and construction that goes into every Convaid Cruiser because the patented fold of the Cruiser *gives your child firm positioning*. In fact, the more your child's body weight presses down, the firmer the upholstery becomes. When you travel, the Cruiser folds easily to fit into your trunk or backseat.

Convaid PRODUCTS INC
P.O. Box 2458 / Palos Verdes, California 90274
310-539-6814 / 1-800-552-1020 TOLL FREE
FAX 310-539-3670

Circle #16



Obviously, a computer program can't take the place of a good teacher. But the Early Learning series from Marblesoft is a tool that helps teachers keep learning fun for early elementary and special education students.

The software is easy to use -- for both the student and the teacher. And when used with a speech synthesizer, there's the added advantage of a human-sounding voice that praises right answers and gently encourages the student after wrong ones.

For more information and a complete product catalog, please call (612) 755-1402.

MARBLESOFT

12301 Central Ave. N.E. Blaine, MN 55434

Circle #136

Infa-Dent®

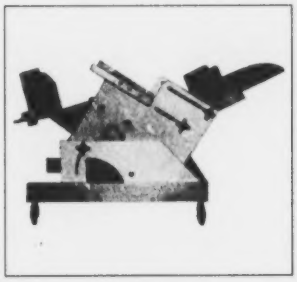
Finger Toothbrush and Gum Massager

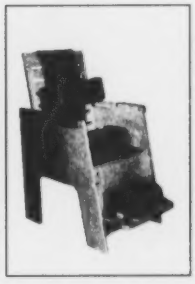
* GENTLY CLEANS TEETH
* MASSAGES GUMS
* EASY TO USE

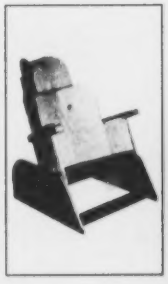
Available At Your Nearest Drug Store

Or Call 1(800) 868-8338

Nu-Tec Health Products,™ Inc Circle #56







My name is Jed, but they call me *"Chairman of the Board"*.

That's because my dad builds all kinds of equipment just for me. Call him for a catalog and an inservice demonstration.

- Products are fully adjustable. Excellent for child evaluations.
- Unique designs which serve the child, parents & professionals.

SPECIAL DESIGNS, inc

CUSTOM EQUIPMENT FOR SPECIAL KIDS

(908)-464-8825

P.O. Box 130, Gillette, NJ 07933

Circle #71

EXCEPTIONAL PARENT

OVER 1000 RESOURCES

Order Now While Supplies Last!

THE EXCEPTIONAL PARENT 1994 RESOURCE GUIDE

DIRECTORIES OF NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS & SERVICES

A Valuable Reference Tool for Parents and Professionals

Need to Learn More About Your Child's Specific Disability?

309

69

26

Need Help Locally?

2

400

Need Help with Technology?

46

53

Need Information About Products & Services?

13

200

To Order Your Copy of This Valuable Resource Guide
Call 1 800 535 1910 or mail in the coupon below

$19.95 Plus $4.00 Shipping & Handling

Mail to: *Exceptional Parent*, Dept 94BAFC, P.O. Box 8045, Brick, NJ 08723 • • • **or call 1-800-535-1910**

❑ Send me _____copy(s) ($19.95 + $4.00 S&H) of *The Exceptional Parent 1994 Resource Guide*

❑ Check Enclosed ❑ Mastercard ❑ Visa

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Expiration Date:

Signature _____

Name _____

Address _____

City _____ State _____ Zip _____

Telephone (____) _____ Fax (____) _____

U.S. Funds Only
These prices are subject to change.
Please allow 4-6 weeks for delivery
Returns must be made within 4 weeks of delivery

EP055DR

110

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

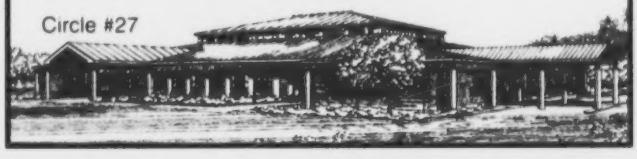
Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27



Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle #75

BERKSHIRE MEADOWS

A private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled

Where a nurturing, home-like atmosphere combines with state-of-the-art facilities and intensive therapy to allow children to achieve their maximum potential.

- *Beautiful campus in the heart of the Berkshire hills with cheery, comfortable semi-private rooms*
- *Innovative learning center with unique, year-round curriculum*
- *Hydrotherapy in an indoor therapy pool and hubbard tank*
- *Augmentative communication systems developed along with total communication*
- *Intensive physical therapy*
- *Around-the-clock advanced medical care*
- *Associations with leading specialists and major medical centers*
- *Affiliation with SUNY*
- *Parent association and open-door visiting*

Contact: Gail W. Charpentier, Director
Berkshire Meadows
RFD #1, 249 North Plain Road
Housatonic, MA 01236

(413) 528-2523

Circle #6

EARLY INTERVENTION

School for the Blind

On October 8, 1986, P.L. (Public Law) 99-457, amendments to the Education of the Handicapped Act (EHA) became law. These amendments included a national reform agenda for increased and improved services for young children with special needs—birth to six years—and their families. This agenda was fueled by the needs of these children and by the documented benefits of early intervention and preschool services. The legislation also recognized the unique role of families by mandating services not only to children with disabilities, but also to their families. In October 1991, this reform agenda was updated through amendments to the Individuals with Disabilities Education Act (IDEA).

Photo: Kim Calabro

Today, a number of accomplishments can be traced to the nationwide reform effort that began in 1986.

All states currently provide services to young children with disabilities and their families. For children in the age range of birth to three, almost 40 states now provide an entitlement to early intervention services. All states ensure the provision of public educational services to all eligible three- through five-year-olds.

Three major portions of IDEA—Part H, Section 619 and EEPCD—have been particularly important to the expansion and improvement of services to young children with disabilities.

Infants and Toddlers with Disabilities (Part H)

Part H of IDEA—a 1986 amendment to what was then known as EHA—was a major piece of federal legislation dealing with services to the very youngest children with disabilities. Part H did not require states to provide early intervention to children from birth to age three, but it offered assistance to states (or territories) that were interested in serving this age group. Under Part H, participating states received federal help in planning and implementing systems of comprehensive, multi-disciplinary, interagency programs for all eligible young children and their families.

Part H requires that statewide service-delivery systems fit each state's unique needs and characteristics. Participating states are asked to work with local communities in designing a family-centered, collaborative, culturally competent and high quality service system. Each governor must designate a lead agency within the state government to plan and oversee the operation of this system. This lead agency is advised and assisted by a gov-

A National Overview

by Pascal Trohanis

Photo: Kim Calabro

Photo: Kim Calabro

ernor-appointed Interagency Coordinating Council (ICC) representing various agencies, service providers, universities and parents.

Preschoolers with Disabilities (Part B/Section 619)

Section 619 of IDEA (an amendment to a previous portion of Part B of the EHA) created greater funding incentives to states to provide a "free appropriate public education" to all eligible three- through five-year-old children with disabilities by the 1991–92 school year. Family services and programming variations are encouraged. In addition, all other requirements of a state's Part B plan for special education and related services—Individualized Education Program (IEP), due process, and Least Restrictive Environment (LRE)—must be met.

Early Education Program for Children with Disabilities (EEPCD)

EEPCD expanded EHA projects known as the Handicapped Children's Early Education Program. Today, there are over 130 EEPCD projects nationwide. These projects include model/demonstration programs, research institutes, inservice training projects, outreach programs and technical assistance. Together, these projects seek to provide information on effective programs and techniques, demonstrate collaboration and inter-project networking and expand the quality and quantity of services to young children.

Accomplishments

Programs across the country are using a variety of collaborative and creative strategies to meet the challenges posed by the Part H and Section 619 of the IDEA legislation. For example, all states have or are developing:

- Coordination plans and agreements with other federal programs serving children and families;
- Policies regarding eligibility, individualized service plans, service coordination, transitions, least restrictive/ most natural environments, procedural safeguards, child identification, health care and diversity;
- Ways to coordinate multiple funding sources to enable their systems to operate effectively and efficiently;
- Broad dissemination of information on successful programs and procedures that will benefit services to children and families;
- A high level of volunteer and collaborative participation, including involvement in the State Interagency Coordinat-ing Council, the council task forces and its committees and local and regional activities;
- Methods to ensure that all professional personnel—early interventionists, teachers, occupational and physical therapists, speech

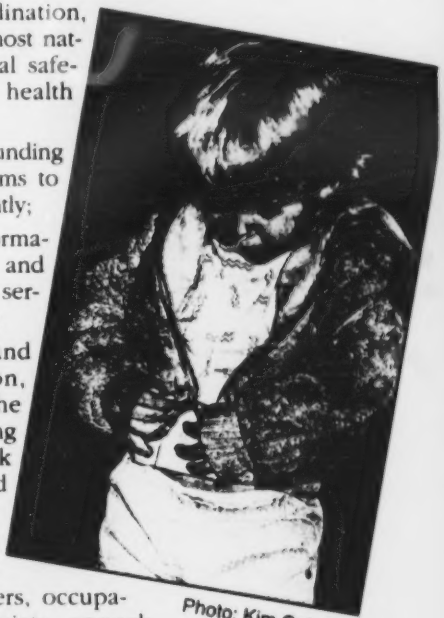


Photo: Kim Calabro

Photo: Perkins School for the Blind

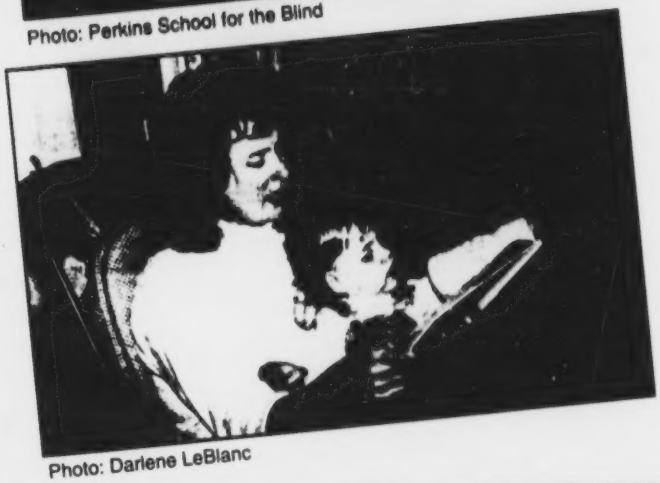


Photo: Darlene LeBlanc

pathologists, psychologists and nurses—are qualified; and

- Public awareness programs, especially related to child identification activities.

Through IDEA, Congress has established a national reform agenda that seeks to expand the opportunities of early intervention and preschool services to more young children with disabilities and their families. IDEA aims to enhance child development, minimize the likelihood of institutionalization and provide much-needed support to families. The promises and dreams of IDEA are becoming a reality through the formation of partnerships, use of new knowledge, tapping of resources and hard work of America's citizens. ■

---

*Pascal Trohanis, Ph.D., is director of the National Early Childhood Technical Assistance System (NEC*TAS) of the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill. For more than 20 years, he has been involved in a variety of efforts to improve and expand services for young children with special needs and their families.*

They'll be Safe n' Secure with ROHO® Cushions for Kids!

We, at ROHO, know that proper positioning is important from day #1. How your child sits will influence the way his bones will grow. With this in mind, we have created ROHO Cushions for Kids.

Individual air cells cushion your child and support his bones and muscles for a longer, more relaxed seating time, while allowing for quick and easy adjustment as he grows.

Because seating is important from day #1, choose ROHO Seating and Positioning Products for Kids.

ROHO® INCORPORATED

For more information, or to locate a dealer nearest you call
(800) 851-3449, or (618) 277-9150. Fax (618) 277-6518

ROHO®, Incorporated & the "crown design" are registered trademarks of ROHO, Inc.

114

Circle #157

Early Intervention Directory

ALABAMA
Part H: Ouida Holder
(205) 281-8780, Ext. 395
ICC: Richard E. Hanan
(205) 271-9209
619: Beverly Hunter
(205) 242-8114

ALASKA
Part H: Susan Jones
(907) 277-1651
ICC: Leslie Yamamoto
(907) 479-0187
619: Richard Smiley
(907) 465-2970

ARIZONA
Part H: Diane Renne
(602) 542-5577
ICC: M. Jeanne Wilcox
(602) 965-9397
619: Lynn Busenbark
(602) 542-3852

ARKANSAS
Part H: Jackie Barentine
(501) 682-8676
ICC: Bill Geiger
(501) 569-8942
619: Sandra Reifeiss
(501) 682-4222

CALIFORNIA
Part H: Julie Jackson
(916) 654-2773
ICC: Marion Karian
(209) 229-2000
619: Betsy Qualls
(916) 657-5212

COLORADO
Part H: April Block
(303) 866-6709
ICC: Barbara Buswell
(719) 531-9400
Boyce Drummond
(719) 687-6596
619: Jane Amundsen
(303) 866-6712

CONNECTICUT
Part H: Joan Brinckerhoff
(203) 638-4208
ICC: Marta Moret
(203) 566-2759
619: Kay Halverson
(203) 638-4205

DELAWARE
Part H: Nancy Wilson
(302) 577-4647
ICC: Chris Long
(302) 856-0038
619: Martha Toomey
(302) 398-8945, 739-4557

Photo: Bradford F. Herzog

DISTRICT OF COLUMBIA
Part H/619: Lena Mills
(202) 208-6675
Sharman Dennis
(202) 727-3755
ICC: Ruth Rucker
(202) 462-3375
619: Lila Vanderhorst
(202) 724-4178

FLORIDA
Part H: Mittie Moffet
(904) 487-1546
Jim Jolley
(904) 487-8718
ICC: Robert Griggs
(407) 896-7881
619: Nancy D. Thomas
(904) 488-6830

GEORGIA
Part H: Wendy Sanders
(404) 657-2727
ICC: Cindy Arceneaux
(404) 279-7971
619: Sara Gill
(404) 656-6319

HAWAII
Part H: Jean Johnson
(808) 957-0066
ICC: Rachel Matsunobu
(808) 877-4527
619: Pam Musick
(808) 737-9575, 737-3720

IDAHO
Part H: Mary Jones
(208) 334-5531/5523
ICC/619: Nolene Weaver
(208) 334-3940

ILLINOIS
Part H: Audrey Witzman
(312) 814-5560
ICC: Maureen Patrick
(312) 421-5200
619: Pam Reising
(217) 782-4601

INDIANA
Part H: Maureen Greer
(317) 232-2429
ICC: James J. Vento
(317) 466-1000
619: Kathleen Hugo
(317) 232-0570/9500

IOWA
Part H: Linda Gleissner
(319) 273-3299
ICC: Edward J. Saunders
(515) 283-0833
619: Joan Turner Clary
(515) 281-3176

KANSAS
Part H: Marnie Campbell
(913) 296-6135/6136
ICC: Nancy Peterson
(913) 864-4954
619: Carol Dermyer
(913) 296-7454

KENTUCKY
Part H: Jim Henson
(502) 564-7700
ICC: Vicky Stayton
(502) 745-4641
619: Debbie Schumacher
(502) 564-7056
Barbara Singleton
(502) 564-7056

LOUISIANA
Part H: Susan Batson
(504) 342-1837
ICC: Janie W. Martin
(504) 924-8034
Rep. Ted Haik
(318) 365-5486
Mollie Alarcon
(504) 838-3900
619: Marybeth Ridgel
(504) 342-3479
Janice Zube
(504) 342-3479

MAINE
Part H: Susan Perry
(207) 289-3272/287-4250
ICC: Helen Zidowecki
(207) 624-5424
619: Joanne C. Holmes
(207) 287-3272

MARYLAND
Part H: Carol Ann Baglin
(410) 333-8100
ICC: Michael Bender
(410) 550-9417
Katherine K. Cooper
(410) 838-9015
619: Nancy Vorobey
(410) 333-2498

MASSACHUSETTS
Part H: Andrea Weiss Schuman
(617) 727-5089/5090
ICC: Thomas R. Miller
(617) 924-3434
619: Elisabeth Schaefer
(617) 338-3300, Ext. 360

MICHIGAN
Part H: Jacquelyn Thompson
(517) 373-2537
ICC: John Lindholm
(906) 786-9300
619: Jan Baxter
(517) 373-8215

MINNESOTA
Part H: Jan Rubenstein
(612) 296-7032
ICC: Lori Lynn Guzman
(612) 891-2240
619: Robyn Widley
(612) 296-5007

MISSISSIPPI
Part H: Hope Bacon
(601) 960-7622
ICC: Hon. Mark Garriga
(601) 864-4011
Shirley Miller
(601) 939-8640
619: Nancy Artigues
(601) 359-3498

Photo: Perkins School for the Blind

Photo: Perkins School for the Blind

MISSOURI
Part H/619:
Melodie Friedebach
(314) 751-0185
ICC: Joyce Coleman
(314) 454-6108

MONTANA
Part H: Jan Spiegle
(406) 444-2995
ICC: Judy Wright
(406) 444-3622
619: Dan McCarthy
(406) 444-4425

NEBRASKA
Part H: Judy Constantin
(402) 471-2471
ICC: Tom Fortune
(402) 436-1907
619: Jan Thelen
(402) 471-4319

NEVADA
Part H: Marilyn K. Walter
(702) 688-2284
ICC: Ann Marek
(702) 687-3140
619: Sharon Rogers
(702) 687-3140

NEW HAMPSHIRE
Part H: Donna Schlachman
(603) 271-5122
ICC: Nate Norris
(603) 271-6693
619: Ruth Littlefield
(603) 271-3741

NEW JERSEY
Part H: Terry Harrison
(609) 777-7713
ICC: Mary E. Lotze
(908) 235-7080
619: Arlene Roth
(609) 292-4692

NEW MEXICO
Part H: Marilyn Price
(505) 827-2573
ICC: Sally Vancuren
(505) 842-9045
619: Diane Turner
(505) 827-6541

NEW YORK
Part H: Frank Zollo
(518) 473-7016
ICC: Nan Songer
(315) 443-4331
619: Cynthia Gallagher
(518) 474-2251

NORTH CAROLINA
Part H: Duncan Munn
(919) 733-3654
ICC: Laurie Collins
(910) 768-8823
619: Mable Hardison
(919) 715-1603
Kathy Baars
(919) 715-1598

NORTH DAKOTA
Part H: Robert Graham
(701) 224-2768
ICC: Nyla Juhl
(701) 777-4532
619: Alan Ekblad
(701) 224-2277

OHIO
Part H: Cindy Oser
(614) 644-8389
ICC: Elizabeth S. Ruppert
(419) 381-3831
619: Karen Sanders
(614) 466-0224

OKLAHOMA
Part H: Cathy Perri
(405) 521-4880
ICC: Candye Chavez
(405) 789-4350, Ext. 223
619: Jill Burroughs
(405) 521-3351/4877

OREGON
Part H: Diana Allen
(503) 378-3598
ICC: Peggy Pietka
(503) 282-8585
619: Nancy Johnson-Dorn
(503) 378-3598

PENNSYLVANIA
Part H: Jacqueline Epstein
(717) 783-8302
ICC: Linda Widman
(717) 652-3962
619: Esther Beck
(717) 783-6889
Rick Price
(717) 783-6913

RHODE ISLAND
Part H: Ron Caldarone
(401) 277-2313/2312
ICC: Peter Dennehy
(401) 277-2385, Ext. 265
Lynn Wells
(401) 245-1149
619: Amy Cohen
(401) 277-2705

SOUTH CAROLINA
Part H: Kathy Purnell
(803) 737-4045/4046
ICC: Susan Smith
(803) 560-6480
619: Mary Ginn
(803) 734-8126

SOUTH DAKOTA
Part H: Barb Lechner
(605) 773-4478
ICC: Judy Struck
(605) 677-5311
619: Deb Barnett
(605) 773-3678

TENNESSEE
Part H/619: Sarah Willis
(615) 741-3537
ICC: Wesley Brown
(615) 929-4192

TEXAS
Part H: Mary Elder
(512) 502-4900
ICC: Pamela S. Marcum
(817) 752-3451
619: Kathy Clayton
(512) 463-9414

UTAH
Part H: Joyce Lacy
(801) 538-6922
ICC: Marianne Johns
(801) 538-6922
619: John Killoran
(801) 538-7700/7708

VERMONT
Part H: Beverly MacCarty
(802) 863-7338
ICC: Shari Rutz
(802) 457-1213
Mary Alice Leonard-Heath
(802) 685-3035
619: Kathy Andrews
(802) 828-3141

VIRGINIA
Part H: Anne Lucas
(804) 786-3710
ICC: John E. Frederick, Jr.
(703) 389-0832
619: Jaye Harvey
(804) 225-2655

WASHINGTON
Part H: Sandy Loerch
(206) 586-5596/8696
ICC: Judith Moore
(206) 325-8477
619: Ann Shureen
(206) 753-0317

WEST VIRGINIA
Part H: Pam Roush
(304) 558-3071
ICC: Ken Price
(304) 766-1986
619: Carol Williams
(304) 558-2696

WISCONSIN
Part H: Susan Robbins
(608) 267-3270
ICC: John Turcott
(608) 828-1305
619: Jenny Lange
(608) 266-9172

WYOMING
Part H: Mitch Brauchie
(307) 777-6972
ICC: Carrie Westling
(307) 235-5097
619: Linda Benoit
(307) 777-6257

AMERICAN SAMOA
Part H: Julia Lyons
011 (684) 633-4929/2697
ICC: Fred Malala
011 (684) 633-4929
619: Linda Avegalio
011 (684) 633-1323/4789

FEDERATED STATES OF MICRONESIA
619: Yosiro Suta
011 (691) 320-2302

GUAM
Part H/619: Faye Mata
011 (671) 646-1416/8396
ICC: Rosanne Ada
011 (671) 646-8396

MARSHALL ISLANDS
619: Kanchi Hosia
011 (692) 625-5261

NORTHERN MARIANA ISLANDS
Part H: Suzanne Lizama
011 (670) 322-9956
619: Priscilla Van Tries
011 (670) 322-9956

PALAU
Part H: Elizabeth Watanabe
011 (680) 488-2537
ICC: Gillian Johannes
011 (680) 488-1907/1632
619: Peter Elechuus
011 (680) 488-2568

PUERTO RICO
Part H: Carmen Aviles
(809) 767-0870, Ext. 2228
ICC: Zaida Fernandez
(809) 753-9082/9080
619: Awilda Torres
(809) 759-7228

U.S. VIRGIN ISLANDS
Part H: Iselyne Hennessey
(809) 777-8804
ICC: Chearoll Looby-Williams
(809) 778-2275
Patrice Harley
(809) 776-6643
619: Wanda Hamilton
(809) 773-7697
Dana Fredebaugh
(809) 776-5802

116

Perspectives on EARLY INTERVENTION

Christel Dawkins, Mona Freedman, Cassie Johnston and Judie Walker are able to offer unique perspectives on early intervention. First, they are parents of children with disabilities who benefited from early intervention programs in their local communities. Then, in the years following their own children's graduation from early intervention, all four became involved professionally with the provision of services to young children in their own states and communities. ***Christel Dawkins*** *was a parent member of the Interagency Coordinating Council in her home state of Louisianna;* ***Mona Freedman*** *is coordinator of the Family Support Network for the Maryland Part H lead agency;* ***Cassie Johnston*** *is coordinator for the Birth to Six Project of Washington state's Parent Training and Information (PTI) Center; and* ***Judie Walker*** *is co-director of Pilot Parent Partnerships, Arizona's PTI Center. Some portions of this article first appeared in the* Early Childhood Bulletin *published by NEC*TAS at the Federation for Children with Special Needs, Boston, MA.*

Eight-year-old Will Dawkins bakes cookies with sister, Claire.

Christel Dawkins:

When my son was two years old, he made no sounds and little eye contact. Will was so beautiful and looked so healthy that no one would believe me when I said there was something wrong. It took a year to get an evaluation and diagnosis of severe language disability. Professionals recommended that I place him in a classroom with non-verbal children learning to sign. Nobody would listen to me when I said that this child would talk. It took another year before I heard his first word—but he did talk.

At eight years of age, Will is now classified as learning disabled. He is in a regular classroom with speech therapy and resource help. He has plenty of friends, is on the soccer team and sings in the children's choir at church. This year he was "narrator" in the second grade Christmas play.

No one knows my child—his strengths, how to motivate him and exactly what he needs—as well as I do. As the parent of a child with special needs this is especially true. In those first months after Will was diagnosed, it was difficult to express this to the professionals working with him. Sometimes all I could do was cry. It was my child's speech therapist who realized that I needed at least as much help as my child. Her careful nurturing of a trusting relationship with the whole family turned us around.

I am also the sibling of a woman with profound disabilities. In the fifties, my parents were given the option of no help at all or letting the state do what was "right"—institutional care. I saw my sister's steady decline and my parents' powerlessness to make changes.

Services have changed dramatically since then. The "family-centered approach" has become the foundation of early intervention. Families are seen as having enormous strengths and making the critical difference that enables a child to reach his or her potential.

In the family-centered approach, families are allowed to choose their role at each stage and professionals are there not to direct, but to support the family

and provide services. Sometimes the family assumes the leadership role, but not always. One mom told me that her role was to love her baby. It is wonderful when professionals recognize the incredible importance of the roles we each choose to play. Nobody was trying to get that mom to assume the role of "advocate" or "case manager." Early intervention works when everyone involved makes a real effort to keep lines of communication open and to collaborate as a team.

Suzanne Johnston, 12 years old.

Cassie Johnston:

For me, the value of early intervention began when someone validated my concerns about my daughter's development. We had many positive interactions with professionals when they saw us as key players. Early intervention also connected us with parent organizations that provided support, information and skills. All of these things helped us become active team leaders for Suzanne. Some professionals probably saw me as an over-involved parent. But last year, Suzanne's speech therapist said that she could "see how all the work and commitment in those early years really paid off."

For the past four years, I have worked at Washington PAVE (Parents Are Vital for Education), the Parent Training and Information Center for Washingon state. Before becoming a paid employee, I did volunteer work and attended many of the PAVE workshops and conferences. PAVE's support was critical for me in those early years.

In my position with PAVE, I have provided support and mentoring to Interagency Coordinating Council (ICC) parents and at the same time, represented a parent perspective among Part H staff members. In the beginning my work felt like a dance—I was afraid of stepping on toes. But then I realized that people hear different music and dance to the music they hear. I have learned to hear and dance to a lot of different music over the last five years. Some I like better than others, but I have come to respect it all.

Mona Freedman:

During infancy, my second-born twin, Andrea, was diagnosed with low muscle tone. She was extremely slow in reaching developmental milestones. Once we admitted that our child had disabilities, our family seemed to become different than other families. We had to deal with professionals, attend IEP meetings and make what seemed like a million appointments. Andrea's twin sister was often left behind with a baby-sitter. Parenting twins can be very challenging, but having a developmentally delayed twin added to the struggle.

Mona Freedman with seven-year-old Andrea.

When Andrea first began receiving services at 18 months of age, progress was slow. As time went on, however, we began to see some positive changes. Our little girl started to flourish and thrive!

Andrea is now seven years old. She is in first grade in the inclusion program at our local elementary school. She has learning disabilities, but she loves "regular" school.

I now work as coordinator of the Family Support Network within Maryland's Infants and Toddlers Part H Program. Part H has generated and supported change at the state level, but now we are shifting our focus to the local level. Using trained "veteran" parents of older children with disabilities as coordinators, local networks have access to all new parents entering the system and can link them immediately with existing support services.

We know now that parents who have learned how to network and support each other become better able to solve their own problems and rely less on professionals. And a better informed parent, naturally, becomes a more effective member of the decision-making team.

Judie Walker:

At Pilot Parent Partnerships, we recognize that families of babies and young children may not seek us out for information on "their rights" or about "what they need to do." We have learned, however, that if we ask them about their dreams and visions for their child and family—and really listen—then we can share with them the ways in which the laws can help them achieve those dreams.

When parents are beginning to find out about their child's disability and special needs, they often hear only what the child won't or can't do. Parents may not be devastated by the fact that their child has a disability, but many are devastated by all the negative things that people say or by the condolences they offer. By talking with another family who has a child with similar needs, families begin to see a more balanced picture. They learn to smile and laugh again. They learn they will be able to be a family—not by someone telling them how, but by offering a living example. Families find out they are not alone. The experienced family offers the new family information and support that helps break the initial isolation.

We get acquainted with families by listening to them and offering information they request. To establish the initial contact we inform community physicians, health care providers, and human service workers about our work and how we might enhance their efforts to build a relationship with the family. We model respect for the family and family decisions.

Pilot Parent Partnerships doesn't tell parents what to do, but listens and offers information and strategies to help them address their priorities. We meet families where they are because we can remember our own feelings of being the "new" parent. We help families to create new visions of possible and desirable futures. ■

A Graduation f 2

This speech was delivered in June 1990, on the occasion of my three-year-old daughter's "graduation" from her early intervention program.

It is appropriate that parents walk with their children at this particular graduation. The first reason for this is that our children need us to get wherever it is they're going—they will, for a long time. But over the last three years, we have come to realize that they also are our co-pilots. They have taken us down many roads we didn't expect to travel. They have introduced us to each other. And they have brought us to places in our minds and hearts that we didn't know existed.

Three-year-old Dana receives her early intervention "diploma."

The second reason is that we parents are graduating from this program just as surely as our children. Long before the staff began talking about family empowerment, some of us parents were very blunt about why we were here. We came because we needed it. If our children also benefited in some way, well, that was even better. But we were the clients in need of service. We came—in bad weather, with colds, throughout the long summer—because we needed to.

The lessons we learned here would fill a book, and someday they might. But a few thoughts come to mind immediately. I don't presume to speak for all the families graduating from this program, but I do speak for myself and a number of others whom I feel privileged to call friends.

We learned a lot about love, unconditional love. And acceptance. At first, the diagnosis of a disability seems like a cruel joke. But then the reality sets in. You realize that all the hopes and dreams a parent normally has for a new baby may not come true—the trips to the playground, the Little League games you wanted to coach, the books or plays you wanted your child to enjoy. You realize that he may not attend your alma mater, and she is not going to be the prettiest bride there ever was. The death of these dreams is a very significant loss—it is a pain that never ever goes away—and so your child may not be very easy to love at first.

For months, you nurse your disappointment while caring for a little person who may have mental retardation, who may have blood drawn weekly from the veins of his neck, who may be unable to move from the blanket on which you lay him, or who can't see you clearly or hear your voice. Then something happens. One day, you realize that this little person has shown more patience, more good humor, more even-temperedness, more perseverance and more acceptance of you and his world than you have ever known. That little person smiles at you in his own way and lets you know that he's been waiting for you—waiting until you were ready—and he has a special place in his heart for you.

Then you realize why you have been given this little person. It isn't because you're some kind of saint. He is here to teach you never to take a spoken word for granted or consider a child's step ordinary. He is here to teach you about a strong spirit, acceptance, loyalty and love in the face of difficulty.

The other lesson that jumps out at me when I think of this program was taught by the other parents. I met these parents first in my assigned support group; later, they became my friends. The lesson is to love and not to judge—not to judge another's motives, pain, sincerity or circumstances. I was not judged by these parents, many of whom faced far more difficult situations than I. If I was frustrated by my daughter's delay in walking, or worried about her minor ear operations, or angry at being tied down at home, my friends would listen, understand and sometimes make me laugh. No one ever denied my pain by telling me to just be thankful that she could stand up, or that she didn't need open heart surgery or that at least I had another normal child. For this, I thank you.

I still find it amazing that people with children of such tremendously different levels of ability could share, sympathize, and come away refreshed and encouraged by each other. I find it amazing that parents of children with some of the most severe disabilities in the program would babysit for my children so that I could get away for the weekend. I find it amazing that we could come together to appreciate and celebrate the little and big milestones in our children's lives.

To be sure, there have been some tears—some of our little friends are not even here to share this day—but there

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

MYDESC™
The Custom Desktop

1-800-4-MYDESC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2241 • MYDESC is a trademark of Rhamdec, Inc.

1
120

have been so many more laughs. So many more days and nights when you came away knowing that you'd be okay, that you could manage, that you weren't the only one in this boat.

I couldn't leave without saying how impressed I have been by the dedication of the staff who work with our children. During the past three years, we have met many professionals and volunteers who have never failed to believe in our children or in us. You are a national treasure, and we thank you.

I would also be remiss if I didn't express appreciation to all the spouses, grandparents and friends who have supported us. It would have been impossible to get our children everywhere they had to go without the people who transported them, baby-sat for our other children and helped in other ways.

Like all graduates, we parents are a little nervous. We came here timid and full of questions. Now we have learned the ropes and have even been bold on several occasions. So now we face a future that is not as simple as our past. To leave early intervention is to acknowledge that our children are getting older and that some of our questions remain unanswered. But I believe that if we remember well the lessons we have learned here, we will learn to live with the questions. And our children will continue to be the wind beneath our wings.

Epilogue

Last September, my daughter Dana, now six years old, began attending the local elementary school her 10-year-old brother also attends. She is partially mainstreamed in a kindergarten class and rides the regular school bus with other neighborhood youngsters. Dana also participates in Daisy Girl Scouts, religious education and dance classes.

The support I continue to receive from other parents I met through early intervention remains a constant in my life. Although our children have gone their separate ways, our parent support group continues to meet every month or so to exchange information and support each other through the ups and downs of our children's lives.

Another thing that doesn't change after early intervention is the need for parents to continue to learn not only about their own children's disability, but also about the educational system, inclusion and other issues. Monitoring your child's education can be so overwhelming, but it's absolutely necessary.

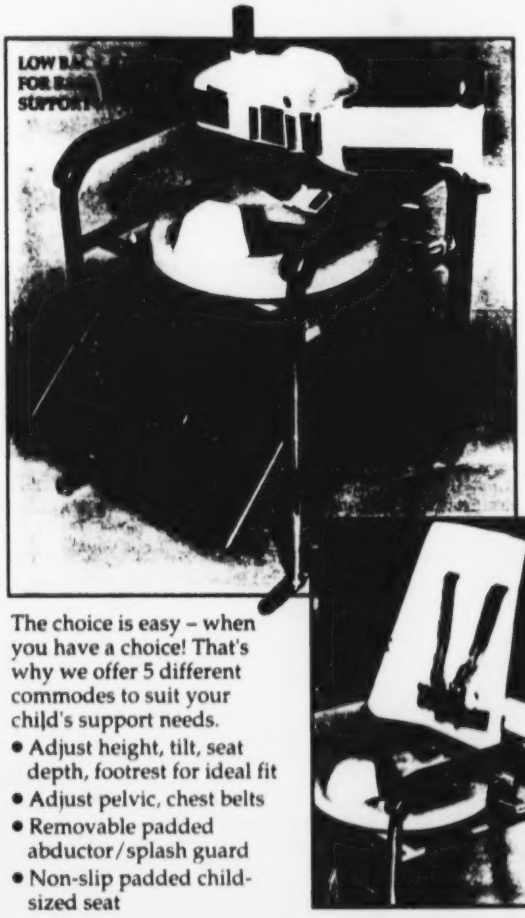
The third thing that doesn't change is that parents are still their children's primary teachers. This is true even though their children may spend the majority of their day someplace else with experts. Parents of children without disabilities impart their values and learning to their children through everyday activities—reading, shopping trips and household chores. We must do the same for our children with disabilities. This is critical in developing our children's self-esteem and making them feel like an integral part of the family. ■

Teresa M. Rafferty is the mother of six-year-old Dana, and ten-year-old Devin. She is a freelance health care writer and president of the PTA at the elementary school her two children attend. Her husband, Tom, is employed by the State of New Jersey as an administrator for Medicaid.

121

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet



The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

Circle #13

COLUMBIA

I'm Bryan's Dad and Part of His Team

by Bob Craig

Bob Craig and son Bryan.

After several years of parenting a child with special needs, I am well aware of how easy it is for fathers to feel left out of the process. The family is much more than "mother and child" and needs to be considered as such. Early childhood specialists at all levels have much more experience with, and may feel more comfortable with mothers.

Have you—as a father—ever have been at a therapy session, parent conference or doctor's visit and felt that no one was talking to you? If so, it's time to take action! Don't allow yourself to be left out. Parenting any child is hard work; parenting a child with special needs is especially tough. Everyone who is in contact with your child on a regular basis must be pulling in the same direction—including you. We don't need to be on the same rope, but we all need to pull in the same direction.

There are many things that we as fathers can do to remain involved in the complex parenting process. My son, Bryan, has diplegic cerebral palsy. During his early days of diagnosis and treatment, it helped me to be the keeper of records. After each significant visit, we asked for a written report. By tending this file, I could keep track of what was going on—even during visits I couldn't attend.

Staying involved means asking questions. At each doctor's visit or parent conference, come prepared with a few questions of your own. Ask your questions as early as possible during each meeting. This keeps service providers mindful of your involvement.

You may not be able to attend therapy sessions with regularity, but you can know all the people your child is seeing, and you can know what they do. It's useful if you can dedicate a few of your vacation days each year to stay in touch with your child's therapists. Ask therapists to recommend specific things that you and your child can work on together—you can call them "father's projects"—and ask for occasional "after-hours" sessions or meetings. Fathers often can provide a different approach toward solving the same problems that Mom is working on. This will give her some essential respite also.

Whatever you do, stay involved! It's important for you as a parent. It's important for your child with special needs. And it's an important statement to professionals on behalf of all the fathers who will come after you. ■

Fathers' Voices is a regular feature of *Exceptional Parent* magazine. This column, coordinated by James May, Project Director of the National Fathers' Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth Street, Bellevue, WA 98008, (206) 747-4004 or (206) 282-1334. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with the National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda, MD.

Mary Ellen and Bob Craig share 10 acres of West Virginia hillside with six-year-old Bryan and nine-year-old Erick, two dogs and numerous wild turkey and deer. Craig works as an instrument specialist at the Robert C. Byrd Health Science Center at the University of West Virginia. Bryan is a full participant in his kindergarten program and Erick is doing well in the third grade. When not chasing after his sons, Craig participates on the West Virginia Family Support Council, the West Virginia Family Voices Campaign and the West Virginia Assistive Technology System.

Helping Parents Help Their Children

Clinician's View

VIDEO EDUCATION for PARENTS

of children with special needs

EASY TO FOLLOW STEPS:

INFANT MASSAGE
How to massage your child for developmental benefits

SUCCESSFUL SELF-FEEDING
How to teach your child to eat independently

POTTY LEARNING
How to help your child toward independent toileting

To Order by Credit Card Call
1-800-500-5065 or
Fax (505) 880-0059

$69.95 each
+ 9% S&H

or Mail your check to: **Clinician's View**
6007 Osuna Rd NE • Albuquerque, NM 87109

Many Other Topics Available Including
RHIZOTOMY SURGERY • MANAGING TUBE FEEDING • POSITIONING
Call or Write for a Complete Catalog

Circle #152

Comfortable. Quiet. Affordable. Leakproof.

Just A Few Reasons Why You Must Try The Ultimate In Cloth Diapers

from the Friendly Earth Co.

★ Sizes newborn to adult ★

Are you throwing money away on disposables? The Friendly Earth Company has the perfect answer with the highest-quality cloth diaper you can buy anywhere.

Leakproof Cloth Diaper

Our revolutionary design is leakproof — the gentle elastic around the legs and waist offer a perfect fit. With 6 plush layers of 100% natural cotton on the inside and waterproof nylon on the outside, they're amazingly comfortable. They feature the ultimate in convenience with an innovative all-in-one design that fastens with either soft velcro closures or durable plastic snaps. No pins or diaper covers needed. Plus, they're ultra absorbent so no extra padding is necessary.

Best of all, our diapers mean incredible savings for you because they're washable and can be used for years. Plus, they're environmentally friendly.

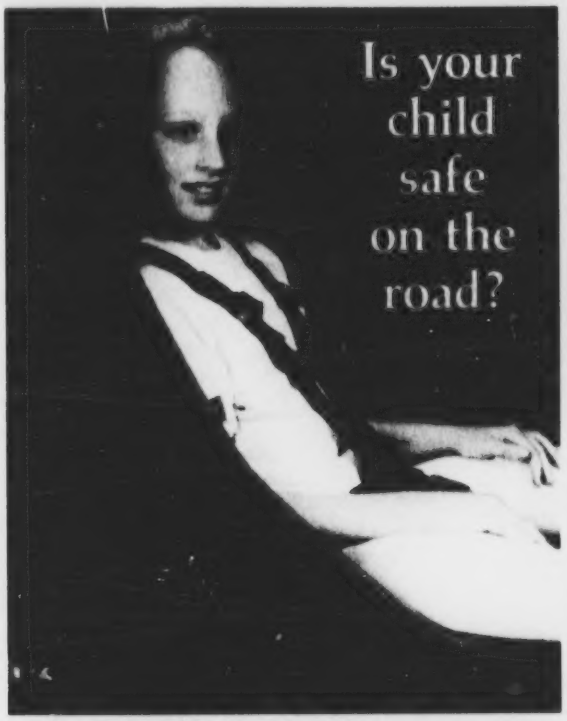
Order Your Sample Today

Call and order your sample diaper today. If you're not 100% satisfied, simply return it within 30 days for a full refund.

Friendly Earth Company, Inc.
Specializing in quality incontinent products
1-800-358-2128

MasterCard VISA

Circle #153



The Columbia Car Seat is your answer
Complete head and body support you can adjust as your child grows . . . in fact, the Columbia Car Seat has passed Federal crash tests for a child from **20 to 102 lbs.**, up to 5 ft. tall!

- Exceeds all Federal safety standards
- Approved for cars, busses, airplanes
- Durable good looks, washable fabric
- Versatile – use as a comfortable support seat anywhere

Ask for our FREE Full Color Catalog of convenient, helpful products

It includes a full line of Toilet Supports so you can choose the exact one to suit your child. They mount and dismount easily on any toilet anywhere.

Contact us for your nearest dealer

COLUMBIA

Judy Heumann

Part One

Clinton Appointee talks about growing up with a disability

Judy Heumann, Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS), U.S. Department of Education, was interviewed by Exceptional Parent *in December 1993. An activist and policy-maker, Heumann worked on Section 504 of the Rehabilitation Act and its reauthorization, the Individuals with Disabilities Education Act, the Americans with Disabilities Act and federal policy guidance governing the provision of personal assistance services to individuals with significant disabilities. She was the first wheelchair rider to be hired by the New York City public schools. Heumann was also co-founder and vice president of the World Institute on Disability, a public policy/research/training organization. This is the first part of our interview.*

I am 46 years old. I have been disabled since I had polio at the age of three. I was born in Philadelphia, but grew up in Brooklyn, New York. I come from a family where both my parents were strong advocates. I don't think they were advocates prior to my having my disability. They learned how to become successful advocates to get what they felt I needed to have.

I started my education at home. I was accepted by other kids in the neighborhood even though I was on home instruction during the day. After school, when the kids came home, I played with my friends. I went to Hebrew school; I was in Brownies and Girl Scouts. I took piano lessons and singing lessons and was very, very involved. Outside of going to school, I was able to do the same things as everybody else in the neighborhood.

> *"I wasn't allowed to go to the school in my neighborhood, because the principal told my mother that I was a fire hazard."*

When I was about nine and a half, I started going to public schools in a segregated program and to camp. I went to Camp Oakhurst and Camp Jened, special camps in New York State. I went to segregated camps, and when I started school, I went to a segregated school.

I was a nine-year-old fire hazard

My mom and a number of other mothers had worked to convince the Board of Education not to force kids in wheelchairs into home instruction. So the Board designated some regular schools in Brooklyn and the other boroughs for kids in wheelchairs to attend. Perhaps there was more than one school in each borough, but there were not very many. I attended segregated classes in a regular elementary school; we weren't integrated for lunch or recess or anything.

The only reason I was in separate classes in elementary school was because I couldn't push my own wheelchair or walk, and I needed help going to the bathroom. I was in classes with children who had different types of disabilities. The more significant their disabilities were, the more they were regarded as not being capable. At that point in my life, I think I learned that people were written off because of the significance of their disability. If they were in a wheelchair, *that* was a problem. If they were in a wheelchair and had a speech disability, that was a bigger problem. And if they were in a wheelchair and had a speech disability *and* had some learning disabilities, that was an even bigger problem. I think this attitude primarily existed in the adults, but it obviously had an adverse impact on us children.

I was bused at least an hour and a half each way to school, when the school in my district was four blocks from my house—maybe ten minutes away. But I wasn't allowed to go to

Above: Judy at age six as a poster child for the Brooklyn Visiting Nurse Association. Bottom: Twelve-year-old Judy (center) plays the role of "Liza" in a school production of "My Fair Lady."

the school in my neighborhood, because the principal told my mother that I was a fire hazard.

High School and College

When I was older, I got bused to Sheepshead Bay High School in East Flatbush, even though Erasmus Hall High School was the one in my district. In high school, I was in a quasi-integrated setting. My classes were with non-disabled students, but I had homeroom with disabled students. I didn't get to participate in many after-school activities because of transportation problems.

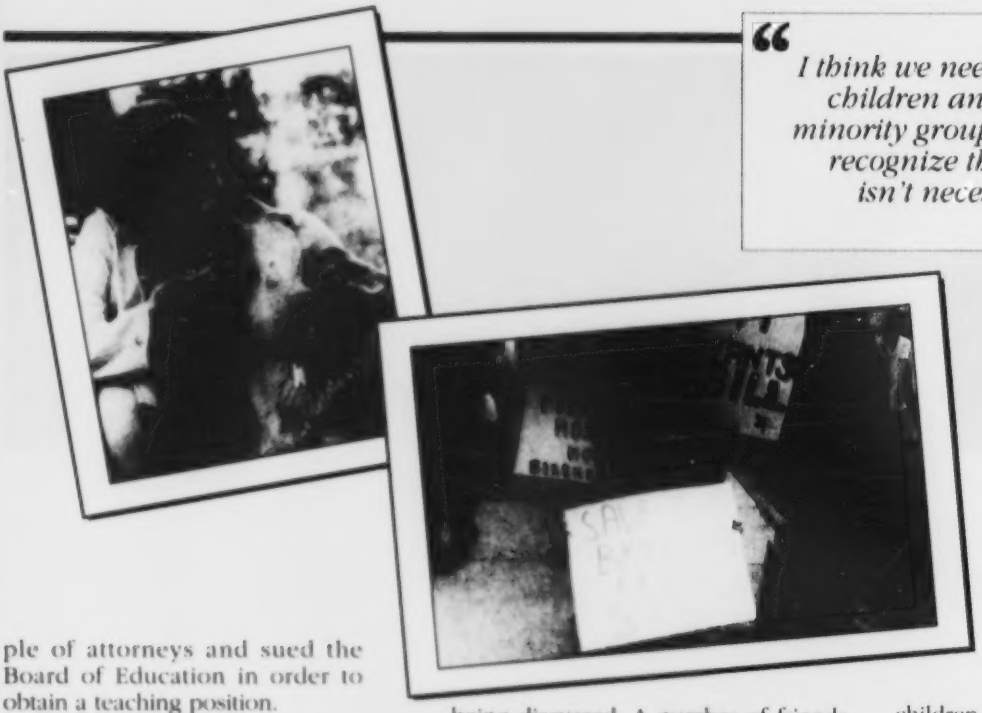
I went to college at Long Island University in Brooklyn. I majored in Speech and Theater because the state rehabilitation agency wouldn't support a major in Education. Students had to demonstrate that they could get a job related to their majors. I could get a job as a speech therapist.

But I was interested in teaching. I knew that I was eventually going to take classes in education so that I could teach. At that time—in the sixties—you only needed twelve credits to become a teacher, because there was a teacher shortage. So as I was beginning my junior year, I started taking classes in education. I also contacted the American Civil Liberties Union to let them know that I thought that I might have a problem once I completed my coursework, because I knew of no people who used wheelchairs who had been hired as teachers. They told me to take the classes and call back if there was a problem. So I took my twelve credits. Nobody in education ever asked me why I was taking these classes. And nobody from the state rehab agency ever asked me either.

Becoming a Teacher

When I graduated in 1970, I registered to take the teaching exam for New York State. The exam included medical, written and oral exams. I passed my oral and written exams; I was failed on the medical exam because of my disability.

I had a friend who was a student reporter for the *New York Times*. He was able to get a *Times* reporter to do a story about my situation. The next day, there was an editorial in the *New York Times*. And the day after that, I was on *The Today Show* (NBC-TV) with Bob Herman. Then I got a cou-



> *"I think we need to look at disabled children and adults like other minority groups. I think we need to recognize that being different isn't necessarily negative."*

Left: Judy with her dog "Lucky," at age 16.

Right: At 19 years of age, Judy joins fellow Long Island University students to protest funding cuts.

ple of attorneys and sued the Board of Education in order to obtain a teaching position.

The Board of Education settled out of court, and I started teaching that September. They found a job for me in the same elementary school I had attended. It was a regular school that had a number of special classes in a separate wing. I taught special education classes for one year without a license. The next year, they moved the regular second grade class down to the first floor. So for my second year there, I taught regular second grade. The next year, they sent all the disabled kids to another school, but I stayed and taught the regular students.

Disabled In Action

While I was teaching in New York, I became very involved in a group called Disabled In Action (DIA), a civil rights organization run by disabled people. We started that group because I had gotten lots and lots of letters and phone calls from disabled people and their families and friends when I was in the newspapers and appearing on TV and radio. When I was doing my interviews, I didn't just talk about trying to get a teaching job. I talked about things that were going on for disabled people all the time—the basic types of discrimination that disabled people faced. A lot of people contacted me to say they were having similar experiences and felt it was important that these issues were being discussed. A number of friends and I decided that we would take all these letters and phone calls and invite people to come to a meeting. And DIA came out of that meeting.

DIA was involved in lots of different issues—anything from access on streets, to access in buildings, to the Rehabilitation Reauthorization Act, to working on the civil rights provisions in the Rehabilitation Act.

On Segregation

The fact that I went to segregated educational settings and camps while growing up was not all negative. The positive part was getting to meet other disabled kids. I think it is very important that disabled children and teenagers meet and have opportunities to socialize with disabled people.

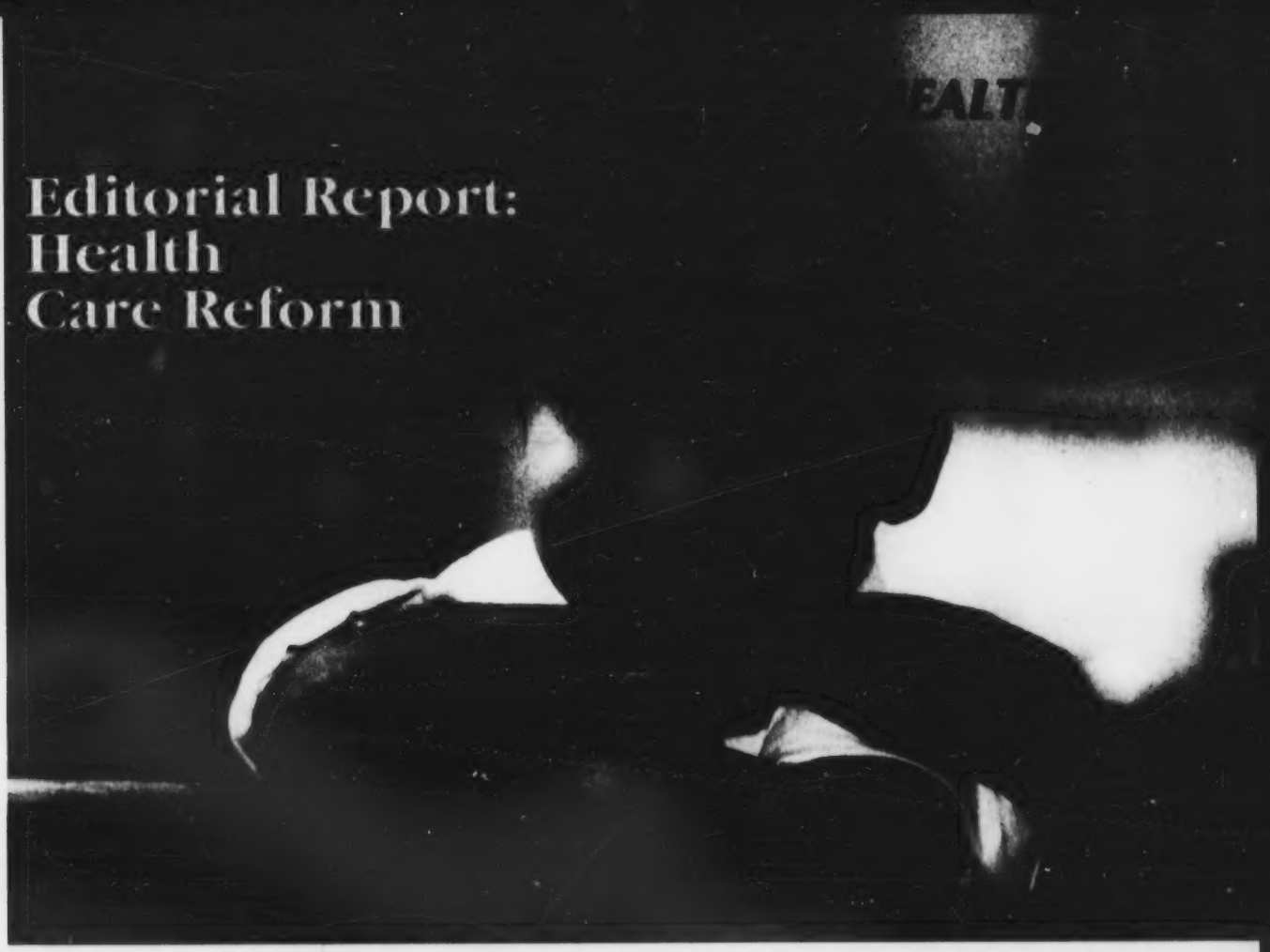
I think it is interesting that in the deaf community, we have accepted that deaf children need to be educated with sufficient numbers of other deaf children—not only to learn academics, but also for socialization purposes. The same type of attention hasn't been paid to kids with other types of disabilities.

I think that sometimes parents of disabled children think that it's better for their kids not to be around other disabled kids because they want to help them become more integrated. I think that attitude is a big mistake. I think we need to look at disabled children and adults like other minority groups. I think we need to recognize that being different isn't necessarily negative.

For me, being able to become friends with disabled kids helped me feel better about myself. Now, as I travel around the country and talk with parents, I do hear some parents say that they believe that it is important for their disabled children to have experiences with their disabled peers. But they are forced to make a choice—to put the child in an inclusive program or to put the child in a segregated program. I don't think it should have to be an either-or situation. I think that parents need to speak for themselves and with their children and tell the schools that they feel it's important for their children to have social experiences with other disabled kids. It's equally important for the non-disabled children to be able—whenever possible—to be exposed to numbers of children with all types of disabilities. ■

The second part of this interview with Judy Heumann will appear in the March 1994 issue of Exceptional Parent. In Part Two, Heumann discusses her current position at OSERS, her plans for more effective implementation of the Individuals with Disabilities Education Act, and other planned initiatives and areas of programmatic emphasis.

Editorial Report: Health Care Reform



Since its introduction in September, we have reported regularly on the progress of President Clinton's health care reform proposal. We have received many letters urging us to continue these reports. We also have heard from a number of parents who shared their concerns—based on various reports—that children with disabilities may be shortchanged under the currently proposed plan. In December, for example, the Associated Press reported on a hearing during which members of the Senate Finance Committee had acknowledged that children with "birth defects or chronic health problems could be excluded from coverage under President Clinton's plan..."

In reviewing the following reports and commentaries, it is essential to remember that—despite perceived inadequacies—the President's proposal offers major reforms that vastly improve many aspects of the current health care system.

Current concerns

Two specific gaps in coverage for children with disabilities have been identified—outpatient rehabilitation services and "customized" durable medical equipment. The proposal's coverage for outpatient rehabilitation services emphasizes the restoration of physical or intellectual functioning following "illness or injury." Accordingly, it appears to omit long-term, outpatient services that many children with disabilities require to maintain current abilities and prevent future problems. Such outpatient services might include physical therapy, occupational therapy and speech and language therapy. Administration officials agree that this is an issue and have urged concerned citizens to contact members of Congress to advocate for the necessary coverage.

"Durable medical equipment" includes seating systems, wheelchairs and many other products. The health reform plan appears to cover "durable medical equipment" and "prosthetic and orthotic devices," while "customized devices" are excluded. Limiting coverage to "off-the-shelf" equipment presents a problem since devices for children are often customized—or individualized. Current health insurance coverage typically has similar limitations requiring parents to pay the difference in cost between the "generic" and "customized" versions of a product. This difference in cost, however, can be substantial.

Knowledgeable advocates have raised additional questions about how other services for children with disabilities will be covered. These include Medicaid payments for early intervention services, so-called "related services" such as therapies within special education programs, and EPSDT (Early and Periodic Screening, Diagnosis and Treatment) services. Concerns have also been raised about coverage for home care and community-based services for people with severe disabilities. Though the reform proposal includes some important services of this kind, it allows individual states to place restrictions on eligibility and types of services provided.

Write Now!

This month's coverage of health care reform includes our adaptation of a recent call to action prepared by the

Consortium of Citizens with Disabilities. We also bring you the personal story of a Virginia family that was forced into bankruptcy by health care costs. We asked Larry Allen to share his family's story because it is all too typical of the health care horror stories that could be written by many families of children (or adults) with disabilities. Anne Lauritzen tells a similarly frightening story in the Informational Forum on page 42. The National Parent Network on Disabilities also urges everyone to get involved (see page 41).

We urge our readers is to make contact with their representatives in Congress. Do not hold back! Parents of children with disabilities and many dedicated advocates are struggling against the vast resources of those in our society who prefer the status quo.

In fact, we believe that it is time for our elected officials to receive letters from the most important individuals involved—children with disabilities and special health care needs. Though most parents and organizations are understandably cautious about involving their children in public advocacy campaigns, we believe that letters from children as well as parents are needed to sufficiently dramatize the urgency of reform in health care for all individuals with disabilities. We hope our readers will encourage their children to write such letters and will send copies to us so that we may publish some in future issues of *Exceptional Parent*.

> *"Letters from children as well as parents are needed."*

Remember—just a few months ago, the "Brady Bill" was facing imminent defeat in Congress. A dramatic groundswell from everyday citizens turned the tide—the "Brady Bill" is now law. The health care reform proposals before Congress are vulnerable. The administration and members of Congress from both political parties are under enormous pressure to "settle for less." This pressure is very powerful—but not insurmountable.

Health Care Taxes

Any discussion of taxes makes elected officials and many citizens very anxious. It may well be necessary to address the need for additional tax revenues to pay for the critical changes in health care that are needed by children and adults with disabilities. However, we believe that the actual net cost to each family for health care—including current health insurance premiums, actual health care expenses which are not covered and possible health care taxes that may be required—may not increase. In addition, we believe that the health security that President Clinton proposes will greatly decrease the ever-present fear hanging over the heads of most Americans—what if a member of my family needs health care and it isn't covered? Think of it—this may be the decade when we will put aside our fears of both nuclear annihilation and catastrophic health needs! The load off our minds could do wonders for our health. ■

S.K., K.S.

5 Models Available Now

The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Circle #43 Photo used by permission Hedstrom Corp. of Bedford, PA

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

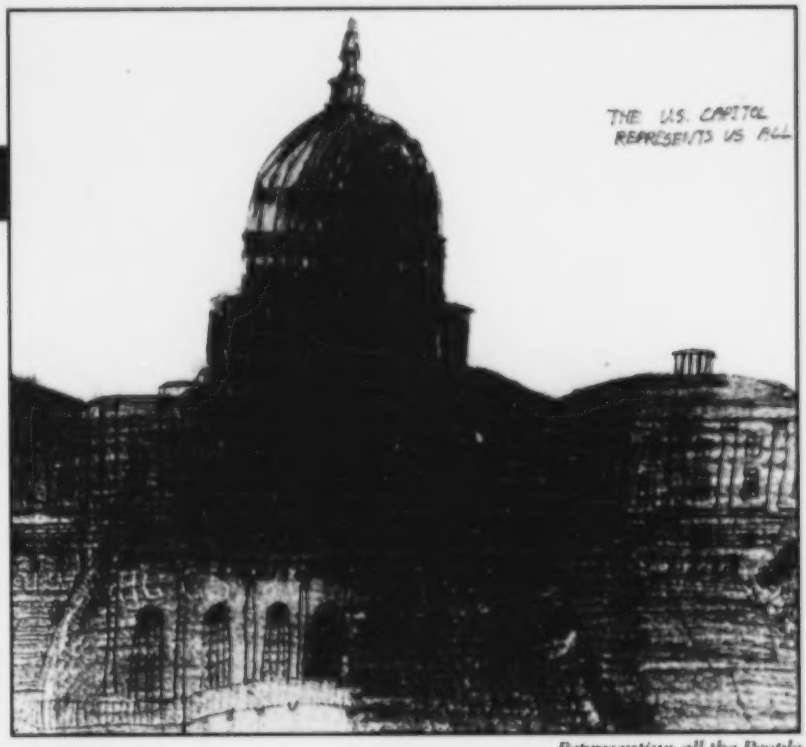
Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle #86

ACTION ALERT



Representing all the People
–Patrick Dermody, Cotting School, Lexington, MA

Health care reform represents an historic moment in American society—one which may not recur for many years. Children and adults with disabilities and their families cannot wait that long for lifetime health care security. Thanks to the leadership of President Bill Clinton and First Lady Hillary Rodham Clinton, we have the opportunity to convince members of the United States Congress to establish a federally-guaranteed right to health care for each American regardless of age, pre-existing condition, current health status, employment status or income.

Unfortunately, many special interests in this $939 billion sector of the country's economy (one-seventh of the gross domestic product) want to maintain the status quo. To that end, they are expending millions of dollars in an attempt to convince the public and members of Congress that we do not need major health care reform and that we cannot afford it. This is a fascinating conclusion since the United States now spends more dollars per capita on health care than any other country, but is the only country in the free world that does not have a national right to health care.

Now, it's up to the 535 members of the United States Congress. We must begin to act today in a united disability voice to help them develop the "political will" to vote for legislation that guarantees a national right to comprehensive health care for all Americans. The President's Health Security Act was officially introduced in November as [Senate bill] S. 1757 and [House of Representatives bill] H.R. 3600. All other bills that have been introduced—except for the President's plan and the "Single Payer" plans (S. 491 and H.R. 1200)—are dangerous to children and adults with disabilities. As Congress begins to work on these bills, your action is needed to ensure that they properly address issues affecting people with disabilities.

Health care reform is the most critical issue that Congress will address in 1994. The results will directly impact the life of every child and adult with a disability in this nation. We in the disability community must convince Congress and the nation that we will not accept—and in fact, will vigorously oppose—tinkering, band-aid solutions masquerading as true reform. We will accept nothing less than comprehensive, lifetime health care security that is guaranteed by law to every single child and adult in America.

Every American with a disability, their family, friends, advocates and service providers in every community must get involved in the health care reform debate immediately. Congress must hear from us now. Your national disability advocates cannot compete with the multi-million dollar budgets of the health insurance, hospital, physician, pharmaceutical, and nursing home industries. Their lobbyists and well-funded political action committees (PACs) are formidable opponents to reform. Your action can and will make the difference!

Time is of the essence! Some Congressional subcommittees are planning to complete their work on the bills as early as the end of February in preparation for votes by the full House and Senate. You, as a voting constituent, must tell your Congressional representatives that you expect them to vote for health care reform that meets the needs of people with disabilities. Tell them about your personal/family experiences. People with disabilities and their families must convince members of Congress that long-term services reform is an essential part of health care reform. Throughout this process, we all must work to protect, strengthen and improve the provisions of the bills as they effect children and adults with disabilities and their families. Without establishing the right to health care, it will not matter what is included in the comprehensive benefit package. The one message we must all say loud and clear is to support the President's commitment to make health care a right for all Americans! ■

Adapted from an "Action Alert" published by the Consortium for Citizens with Disabilities

Riding the Health Care Roller Coaster

by Larry Allen

Enjoying a snowy day: *Clockwise from left, 10-year-old Larry, mom Michelle, 15-year-old Michelle and eight-year-old Michael.*

Being asked to relate our family's story has proven to be an emotional roller coaster ride. To this day, we aren't sure where, when and how this will end. We thank God every day for allowing us to enjoy the good times and accept the bad times as dark moments that will pass.

Our story began in 1978, with the birth of our oldest daughter. Shortly after Michelle's birth, we received a phone call from her doctor, who told us that she had sickle cell anemia. We had no idea what to expect.

> **"We realize that we are one major illness away from bankruptcy again."**

Michelle didn't get sick until she was three. When she had her first crisis, a painful episode requiring hospitalization, we had a rude awakening—our health care carrier refused to pay some of her bills. As Michelle got older, her medical problems worsened, requiring more frequent and longer hospitalizations. The bills kept growing, yet our income was getting smaller.

Our next step was to talk with some financial counselors, all of whom recommended declaring bankruptcy. One month after filing Chapter 13, we needed to bring Michelle to the hospital. The hospital refused to administer treatment, demanding to know how the bills would be paid. It took our attorney four hours to explain the situation before they would even examine her. The worst part was realizing that if the hospital continued to deny her treatment, we had nowhere else to turn—the other area hospitals were not as well equipped.

At this point, my wife had to quit her job. Michelle was getting sick more often and someone had to be with her when she was ill—whether or not she was hospitalized. We learned this the hard way when Michelle was almost given a chemotherapy treatment intended for another child with the same first name.

Our second son, Larry, was born in 1983. Prenatal testing showed that he was healthy. In 1985, my wife became pregnant with our third child, Michael. Again, prenatal tests for sickle cell anemia came back negative. But this time the tests were wrong. At three months of age, Michael was diagnosed with sickle beta thalassemia.

Michael's illness was much worse than his sister's. By the time he was two years old, he had already been hospitalized 15 times. Michael's doctor told us to prepare for the worst, because his body was wearing out. They didn't think he would live another six months, but we could see too much life in Michael to give up. We knew we had to find help elsewhere, so we moved to another state where our children could receive better medical care.

In the last 15 years, we have never had one moment when we could sit back, relax and regroup. We are still dealing with a tremendous emotional and financial burden. We realize that we are one major illness away from bankruptcy again. There are constant challenges—keeping the

utilities turned on, paying the mortgage and keeping food on the table.

In 1993, my wife and I were invited to a human genetics conference, where we heard about some of the research into new technologies that may one day lead to cures for many genetic disorders. We also heard from others experiencing similar problems financing health care. This was an emotional lift. For so long, we had felt like we were all alone with these problems.

Prior to this conference, if we had been asked to relate our story to others, we would have talked about the pain our children endure and the guilt and depression we as parents live with everyday. We would have spoken about our loneliness and fear. About being told we'd be better off on welfare. About feeling out of place—even around family and friends. And about worrying that I might lose my job, because when both children are sick, it requires both of us to take care of them. But, now there is one more thing we can speak of—hope. ■

Larry and Michelle Allen live in Chesterfield County, VA with their three children. They are members of the Mid-Atlantic Regional Human Genetics Network (MARHGN) and the Virginia Sickle Cell Awareness Program of the Medical College of Virginia (VASCAP). Their son Michael was Virginia's 1993 sickle cell poster child.

Meeting the Governor: *As his state's 1993 sickle cell poster child, Michael, along with his mother and sister Michelle, met Virginia Governor Douglas Wilder.*

THE WATER WALKER

* Improves coordination, postural control and muscle tone.
* Provides independence.
* Secured in center with belt or seat.
* Trade-in policy.
* S.M.L
* Covered by most insurance companies.

* Prone or supine support.
* Contour lines that allow use of arms and legs.
* Straps to secure person on float.
* Pillow for head support.
* S.M.L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
123 Haymac Street
Kalamazoo, MI 49004
(616) 349-9049

VISA MasterCard

Circle #150

Crystal Springs School

A PROGRAM OF THE
INSTITUTE FOR DEVELOPMENTAL DISABILTIES, INC.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availability.
- Licensed by the Massachusetts Office for Children.
- Approved by the Massachusetts Department of Education.
- Member of the Massachusetts Association of Approved Private Schools.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537

Circle #151

Home Away From Home

Quality care in a state-of-the-art medically oriented, yet home-like, facility for chronically ill infants, children, and young adults. A one of a kind program staffed by doctors, nurses, therapists, and teachers. If you are thinking about having your loved one cared for outside your home, consider Hacienda de los Angeles with 26 years of experience helping families and their chronically ill family members. Hacienda is located in a semi-rural setting bordered by beautiful South Mountain Park, yet is less than five minutes from the Owens Medical Center.

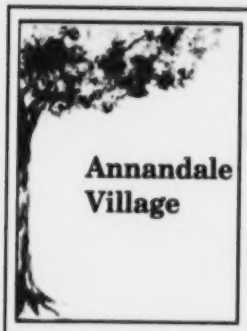
Hacienda's comprehensive program offers:

- Specialized care for individuals with tracheostomies and those who are ventilator dependent.
- A new facility staffed by professional yet caring employees.
- Open door 24-hour visitation.
- Physician services and round-the-clock nursing care.
- Twenty-four hour respiratory therapy.
- In-house physical, occupational, and speech therapy.
- Nutritional services by a certified nutritionist.
- On-grounds and public school based educational services.
- Private and semi-private rooms.
- Individualized programming designed to allow your family member to reach his/her full potential.
- In-house specialized equipment construction and equipment adaptation.
- Transportation in specially equipped vehicles.

Hacienda de los Angeles, Inc.

In Special Lives, We Make A Difference

1402 East South Mountain, Phoenix, AZ 85040
(602) 243-4231
William J. Timmons, Executive Director Circle #154



Annandale Village

"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for adults with developmental disabilities. Residential and day/evening programs and services.

- Paid Job Training
- Arts Activities.
- Therapeutic recreation.
- Case management.
- 125-acre wooded environment.

Annandale at Suwanee, Inc.
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381

"MAXIMIZING INDIVIDUAL POTENTIAL"

- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

FOTO FACE, the Original Momy-Dady Doll provides a child with the comfort and security of the familiar face of a loving parent or friend. Ideal for times away from home and family. Send a clear photo (Color or B&W) with check or money order for $12.99 plus $3.00 shipping and you'll receive a 13" stuffed cotton doll with colorful T-shirt and photographic face. Ethnic dolls available. All photos returned. 2-4 weeks delivery.
Momy-Dady Doll
Box 487, Dept EP
Flourtown, PA 19031
(800) DADY-DOLL

SHEVET ACHIM in conjunction with YACHAD/NCSY is a new & exciting summer program in an Israeli Kibbutz. This four week program is designed specifically for high functioning Jewish young adults with developmental disabilities. Located in Kibbutz Ein Zurim, central Israel. Sabbath and Kosher dietary laws observed.

SHEVET ACHIM
63-67 108th Street
Forest Hills, New York
(718) 997-117 New York
(213) 651-1255 Los Angeles
(312) 764-4019 Chicago

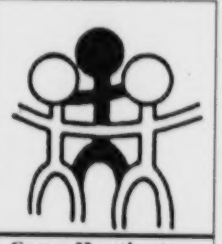
EXCEPTIONAL PARENT MAGAZINE IS NOW PUBLISHING MONTHLY!

Only $24.00 for 12 issues

To order your subscription call:

1-800-247-8080

($30.00 Canadian; $33.00 Foreign)



Camp Huntington
33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:

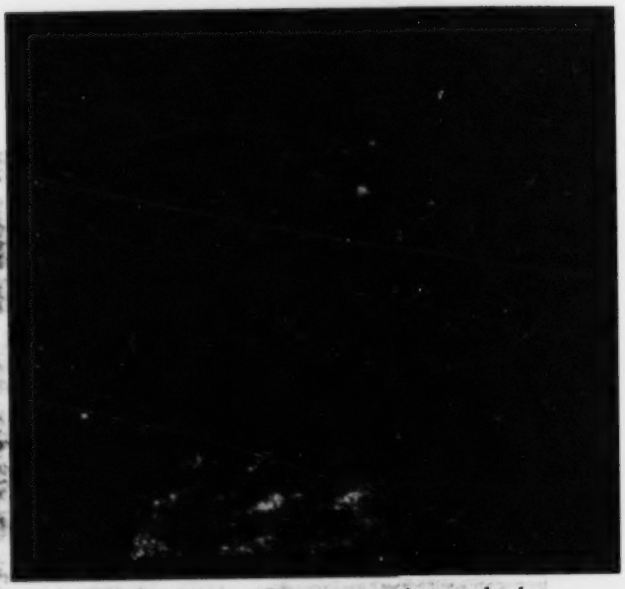
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 31st year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 2440
(914) 687-7840

The Helmet

by Joni Pelta



Mike Pelta works on an art project at school

My son wears a bright red helmet for protection. No, he's not an all-pro linebacker; he's a child who has been diagnosed with a "nebulous developmental delay"—though medical professionals debate whether apraxia might be a more appropriate description. Lacking a precise diagnosis, Mike is simply a three-year-old who is more clumsy than the norm.

I've had a love/hate relationship with the helmet from the start. At first, I resented the fact that Mike needed to wear one at all. The first plastic ones the physical therapist showed me looked so clinical and strange. They were also inappropriate for our humid southern climate. Mike would sweat profusely whenever he wore his new headgear.

We shopped around in many toy and bike shops to find just the right helmet. For a few months, he wore one that seemed to need adjusting every time he sneezed. After further experimentation, we bought the helmet he now wears. Despite its startling red color, it is more forgiving and needs less attention than any other we'd tried.

Like most parents, I hated the idea of my child needing any special equipment that would instantly allow him to be labeled as "different" or having "special needs." While a helmet is not as obvious an aid as a wheelchair or hearing aid, there still aren't many children toddling around with one. But after Mike fell against a glass table at the bank and needed 12 stitches, my husband and I decided the protection his helmet provided was more important than the stares, questions and comments it elicited.

When strangers at restaurants and other public places would ask about the helmet, my responses ranged from simple explanations of Mike's situation to outright rudeness. I wondered whether people using wheelchairs, walkers or other, more standard aids got as many foolish questions as we did, and why strangers felt they had the right to know everything about my child.

I remember the time when just as someone asked about the helmet, Mike tripped over a nonexistent piece of dirt and fell to the floor. "I can see why he needs it!" one of them said, and they all laughed. It bothers me enough that he needs the helmet, but stupid comments like this hurt a lot also.

These days I have a more assertive attitude about handling situations with the helmet. Last month, I took Mike and his brother to a local indoor playground that had slides, ball pits to jump in, and mazes to climb through. We were having fun until an employee approached us. Another patron had complained that the helmet had "bumped" her child and the manager wanted me to either remove the helmet or else "watch Mike like a hawk." As if I don't always watch Mike as carefully as I can when I'm in these places!

Would a place like this ask a person with a walker to get rid of it? Would they tell a child with a hearing aid to take it off? I was so stunned that it was ten minutes before I recovered enough to ask if I could speak to the manager, only to be told that he or she had left. I was too angry to just leave and pretend the incident had never happened. When I got home, I wrote the manager a letter. Later, I got a very sincere letter of apology with some gift certificates for a return visit.

Not every situation involving Mike's helmet has been hurtful. We've learned to keep our sense of humor. Once, when asked about Mike's helmet at synagogue, I replied that he wore it in lieu of a yarmulke. This explanation was accepted with no further questions.

Then there was the time our family was out shopping for a new car. The salesman kept peering at Mike. I

continued on page 60

BRAUN

THE ANSWER TO ALL YOUR MOBILITY NEEDS.

U

1-800-THE LIFT

THE NATIONAL PARENT NETWORK ON DISABILITIES BOARD OF DIRECTORS

- Carol Blades, Special Education Action Committee (SEAC), Mobile, AL
- Richard Burden, IN*SOURCE, South Bend, IN
- Joanne Butts, Washington PAVE, Tacoma, WA,Vice President, NPND.
- Amparo Crespo DeCastro, Asociacion de Padres Por Bienestar de Niños, Impedidos de PR, Inc., Rio Piedras, PR
- Connie Curtin, Vermont Parent Information Center, Winooski, VT
- Diana Cuthbertson, Statewide Parent Advocacy Network (SPAN), Westfield, NJ, President, NPND.
- Christine Davis, Parent Union for Public Schools, Philadelphia, PA, Treasurer, NPND.
- Kathryn Erickson, Pathfinder Services of North Dakota, Minot, ND
- Paula Goldberg, PACER Center, Minneapolis, MN
- Sweet Alice Harris, Parents of Watts, Los Angeles, CA
- Connie Hawkins, Exceptional Children's Assistance Center (ECAC), Davidson, NC, Past President, NPND.
- Bonnie Johnson, Arkansas Parent Support and Information Network, Little Rock, AR
- Joan Kilburn, MATRIX, A Parent Network & Resource Center, San Rafael, CA
- Sue Pratt, CAUSE, Lansing, MI, Vice President, NPND.
- Pam Steneberg, Disability Rights Education & Defense Fund, Berkeley, CA, Secretary, NPND.

- Patricia Smith, Executive Director, NPND

Health Care Reform Misses Persons with Disabilities

by Larry Searcy
Director of NPND
Government Relations

Currently, the Clinton health care reform proposal does not adequately address the needs of children or adults with disabilities. This omission has been admitted by Judy Feder, Deputy Assistant Secretary of the Department of Health and Human Services in testimony before the Senate and pointed out by Dr. C. Everett Koop, former U.S. Surgeon General, in remarks he recently made.

We must make our concerns known to the Congress as never before or face the likelihood of a national health care system that is less responsive to the needs of our children than our current system.

Your members of Congress must hear from you now about the need to assure that people with disabilities be included in any plan of national health care. Most importantly, they must understand that we are united, we have a common voice in Washington, and we are closely watching what our Congresspersons do to respond to our needs!

If your Congressional representatives do not hear from you, the chances of attaining reform that meets the needs of people with disabilities are slim to nonexistent.

What to do:

- Meet with your members of Congress at their local offices.

  Be assertive, insist on seeing your Congressperson or Senator face-to-face. Failing that, insist on seeing the local Chief of Staff.

- Participate in town meetings, open forums, hearings, and similar events where your national politicians will be present.
- Work with other disability and consumer-oriented groups (e.g. family, children, women's, religious, professional, labor, and business organizations) to send a coordinated message to your elected politicians.

  In addition to joint letters and meetings, consider staging public events like consumer hearings around your state that highlight the health needs of persons with disabilities. Whatever sort of events you plan, aim at gaining coverage in the local press.

- Contact your physician and related health professionals and solicit their support. Ask them to communicate with their professional organizations in support of services needed by children and adults with disabilities.
- Prepare personal stories about the importance of health care and long-term services reform. Tell your real-life horror stories about:

  - Non-treatment of health conditions or about discrimination in the present health care system;
  - Impoverishment or other severe financial circumstances stemming from costly health insurance premiums, high medical expenses or unfair existing insurance practices;
  - Work disincentives resulting in continued unwanted dependency on public assistance.

- Write and encourage others to write letters or op-ed articles for the local paper on the health care experiences and needs of people with disabilities.

What to Say:

1. People with disabilities and those who work with and care about them want health care reform. Reform must be accomplished now! It cannot be put off!
2. Access to high quality health care is the right of all Americans, including people with disabilities.
3. The minimum acceptable health care benefits package must be comprehensive and include habilitative and

Next Page:

- **One Childs Profile** *by Anne Lauritzen*
- **"All Children Belong" to Hold National Teleconference**

For information about the NPND, please write: The National Parent Network on Disabilities, 1600 Prince Street, Ste. 115, Alexandria, VA 22314 or call (703) 684-6763.

rehabilitative therapies, customized durable medical equipment, home health services, mental health and substance abuse services—without arbitrary caps or limits.

4. Long-term services and personal assistance services must be a part of the benefits package.
5. Discriminatory practices such as pre-existing condition exclusions must be eliminated. The health care system must comply with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.
6. Consumer involvement must be a part of the system. The system must have built-in consumer protections and quality assurance mechanisms to ensure that people with disabilities get the services that they need.
7. People must not lose access to services that they presently have either through private coverage or Medicaid.
8. A full array of prevention services such as Early Periodic Screening Diagnosis and Treatment must be kept in place. We must also keep Medicaid services that are often utilized in conjunction with Part H services or supportive services provided in conjunction with Individual-ized Education Plans mandated in IDEA.
9. Identify yourself as a member of or as supporting the National Parent Network on Disabilities.*

Please do your part to make health care and long-term services a reality. Let's make sure that our children and adults with disabilities are not left out of legislation that will impact us for the next twenty years or more!

** Excerpted from an "NPND alert" sent to NPND members on December 15, 1993. The full alert and the NPND "Principles of Health Care Reform" are available to all NPND members. This information was based on data compiled by the Consortium for Citizens with Disabilities.*

Networking is information from the National Parent Network on Disabilities. The Network is a membership organization open to all agencies, organizations, parent centers, parent groups, professionals, and all individuals concerned with the quality of life for people with disabilities.

Patricia M. Smith — Executive Director
Connie K. Hawkins — Editor

One Child's Profile

by Anne Lauritzen

My son Drew, now 18 years old, was born with spina bifida. Because of the spina bifida, Drew has neurological, orthopedic, urological, hearing and cognitive impairments. He is paralyzed below the waist and uses a customized wheelchair. Five to six doctors are required to maintain Drew's health. At least two of his specialists are located in another state.

Drew's medical needs have forced our family to put him on the comprehensive health insurance policy that Nebraska has developed for those with pre-existing conditions who have not been able to obtain other insurance. Drew's current policy serves his basic needs—other than that we pay a $120.00 per month premium just for him, and the insurance company continues not to understand how his unique medical needs differ from those of the generally healthy population.

Because we have chosen this policy for Drew we cannot access the Medicaid system. We could drop this policy and get him covered by Medicaid, but then we would be less able to take Drew to the out-of-state specialists he needs. It puts us in a continuous dilemma regarding the best care for him and its continuing costs. We incur many costs every month that are never covered by his current insurance policy but might be covered by Medicaid.

As I read the information about health care reform in the newspaper and from disability coalitions, it seems that the plan does not address the need for specialized health care for many citizens, particularly those with disabilities. I am disturbed that the plan still has an acute care/institutional bias and does not place enough emphasis on family, home and community services. Coverage must go beyond the illness and injury perspective to include those with congenital conditions and aging. Persons with physical disabilities do not improve in their functions to a point of wellness, but they need maintenance and rehabilitative services and supports in order to function in the community.

To maintain his health, health care reform must give Drew a plan that is based on his needs—he will need long-term care in the home and community. He will need home supports, access to specialists in other states, access to physicians that have specialized knowledge about his disability, physical and occupational therapy, hearing aids covered by insurance and customized equipment.

I support universal access for all citizens, with no pre-existing condition exclusions; the guaranteed comprehensive benefit package; portability and the recognition that long-term care is a crucial component.

"All Children Belong" to Hold National Teleconference

"All Children Belong," a national inclusion awareness and training program supported by the DeWitt Wallace–Reader's Digest Fund, will hold its first national teleconference training event on March 9, 1994. The three-hour session—currently scheduled to begin at 1:30 p.m. EST—will focus on providing an overview of supported inclusive education and community-wide supported inclusion. Participating project sites will be able to interact with the national "All Children Belong" training staff.

If you are interested in gaining access to the teleconference please contact Larry Searcy at the National Parent Network on Disabilities (703-684-6763).

NPND Executive Director Patricia McGill Smith was inducted into the Professionals Offering Work Employment Resources for Persons with Disabilities (POWERS) Hall of Fame. This honor came in recognition of her life-long service to children with disabilities and their families.

AT NATIONAL MOBILITY GREAT PRICES ON OUR VANS COME STANDARD

THE EQUALIZER I Here's the top selling 1993 Dodge Grand Caravan, elegantly appointed and fully accessible. Easy-entry, lowered floors eliminate the need for a lift. Choose manual or automatic ramp, air kneel options, choice of seating arrangments...and the quality you expect from Chrysler. $500 Chrysler P-CAP rebate available to qualified buyers.

THE EQUALIZER ADA Now for the individual who sits tall in their wheelchair, we would like to introduce our Raised Steel Roof Van. The same quality you have come to expect from our Equalizer I, with a 56 1/2" door height and 61" of interior headroom.

National Mobility Corp.

3000B Windsor Ct.
P.O. Box 4525
Elkhart, IN 46514

XX/XX/XX

Mr. or Mrs. Public
Any Street
Hometown, USA

Dear Mr. or Mrs. Public:

Thank you for responding to our advertisement in the Exceptional Parent magazine. Now you can transport your son or daughter in a vehicle that drives like an automobile and fits in any standard garage. We promise to make the purchase of your new vehicle as convenient as possible.

Below is a quote on the van you inquired about:

Equalizer I

Total Price $27,962.00

1993 Dodge Grand Caravan with Power Windows and Locks.

Conversion Includes:

Physically Challenged Accessible Conversion
(Lowering of Floor 10")
Quick Release Passenger Seat
Manual Aluminum Swing-away Ramp
Wheelchair Tie Down Points
Tie Down Securement System (1)
33" Seatbelt Extension (1)

If you would prefer the Dodge Caravan (short Wheelbase) please deduct $1600.00.

*Above price is F.O.B. Elkhart, Indiana. Delivery to your home is available.

**Chrysler P-CAP Rebate of $500.00 to be sent directly to you after delivery of vehicle.

Thank you again for your interest in our products. Under normal circumstances, a deposit of 20% is due upon placement of order. Please contact us at our 800 number listed below with your order.

With Kind Regards,

David A. Baxter
Director Retail Sales

FACTORY DIRECT SAVES YOU THOUSANDS!
Financing Available through Chrysler Credit.
Ask about our rental programs.
1-800-528-3769

National Mobility Corp.

Circle #159

continued from page 4

Winston Churchill, Albert Einstein and Hans Christian Anderson had learning disabilities. Some children with LD have that kind of potential—some are talented or gifted—but almost all are thought at one time or another to be lazy and unmotivated. Or retarded.

By definition they are not retarded! Learning disability is a specific diagnosis. It includes the presumption of normal or better intelligence. It requires remediation based on that presumption. For an authority like *Exceptional Parent* to use "Down syndrome" and "learning disability" interchangeably alters that presumption.

This really is not about labeling. It is about differential diagnosis. I am probably especially sensitive to this because our three sons had needs so like and so *unlike* those of his brothers. We had to strive constantly to find what was best for each of them individually—always with the prayer that if we came as close as we could to making right decisions for each one, the impact on the whole family would be right, too.

So, M.P. of Indiana, when you say you're certain of my motivation, and ascribe to me a motive that's not mine, I have to try again to say it better.

P.P. of Ohio, no, of course, kids with learning disabilities are not more valuable. But they are *as* valuable and as entitled to education specific to their needs. I never meant that "those with cognitive developmental delays are less deserving of service," but the truth is that they have had much more service for many more years than children with learning disabilities.

E.P.K. of New York, I loved reading that your son will graduate from high school with a "full academic diploma!" I love that, but I would not love him more than I'd love those who never learn so much. As our child's retardation became more and more profound, our love grew and grew. You're right, it's not about "an IQ number."

P.B. of Georgia thought my remarks insensitive and based on ignorance. I hope I'm neither. I have known many children with Down syndrome and read of even more. In all the years I've subscribed to *Exceptional Parent*, my favorite article was one called "Proof of the Pudding," a mother's story of a beautiful and accomplished little girl who had Down syndrome (May/June 1974).

That was my favorite, though I have twice been published in *Exceptional Parent* myself. "Loving a Special Child," about my eldest son, was reprinted in *Readers' Digest*. "Tribute to a C Student," about my son with learning disabilities, has been reprinted in a lot of school newsletters.

For many years I have been volunteer editor of *Our Kids* magazine for the Parent Section of the Alexander Graham Bell Association for the Deaf. I have done everything I've known to do to make things better for my children—and yours. I always thought my biggest contribution had been writing about our children, so it's ironic that I could not write a letter to the editor without offending those with whom I feel I share the most.

I hope that the five who wrote (and any other readers who were hurt by what I wrote) will understand now. If I still haven't made my point, I hope you'll forgive me. I never meant to hurt you or your children.

Phyllis Feibelman
3637 Longview Lane
Mobile, AL 36608
(Name and address printed by request)

FREE CATALOG!

- Books
- Posters
- Slide Shows
- Postcards
- Buttons
- T-Shirts
- Sweatshirts
- Tote Bags

Write or call for a free catalog:

Human Policy Press, Center on Human Policy
Syracuse University • P.O. Box 127, Dept. A
University Station • Syracuse, NY 13210
315-443-3851

Circle #156

STROLL INTO A NEW WORLD

Not only can you take your child to places you both would like to go, our **SPECIAL NEEDS STROLLER PACK** will give your child a whole new outlook.

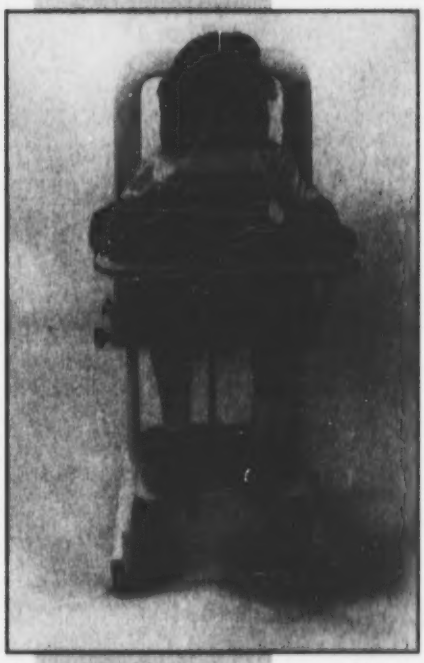
STROLLER Pack
A Way of Life

Call for Information
1-800-487-9652
SKAGGS & INGALLS INC.

Circle #78

Purchasing Seating Equipment: Tips for Parents

Many children with physical disabilities need assistance in order to best use their abilities and be comfortable while lying down, sitting or standing. Positioning refers to the process of establishing the most effective way to assist such a child. When properly positioned, a child has the postural support needed to interact with people and activities without being concerned with losing balance or falling and has better control of body movements. Proper positioning can improve circulation, breathing and digestion. It may also prevent some bone deformities, muscle problems and skin problems.



Positioning Aid Chair, Consumer Care Products, Inc., Sheboygan, WI.

This article focuses on buying equipment for seating. Accordingly, the terms "seating/positioning equipment" or "system" will be used. The buying guidelines in this article also apply to other types of positioning equipment. Choosing the best seating/positioning system for a child requires time and effort, but it is time well spent. Here are some tips that can help.

Adopt a team approach when considering equipment choices. In addition to parents and child, the team may consist of an occupational therapist and/or physical therapist, a technical person such as a rehabilitation engineer, a physician knowledgeable about positioning, and an adaptive medical equipment dealer. Teachers, social workers or rehabilitation nurses may also make useful suggestions. The team approach should be an ongoing process, as there is always new knowledge and equipment available that may help your child.

For some children, readily available seating systems can be adapted to meet the child's specific needs. The companies listed at the end of this article are sources for such systems. For other children, however, highly individualized systems may need to be created; some clinical settings are equipped to create these.

Medical equipment dealers will often be glad to give names of other parents as references. This can be helpful, but remember that what works for one child may not necessarily work for yours. Every child is a unique individual, and is likely to have different positioning needs.

If the equipment is covered by health insurance, be sure to review the insurance company's contract with the manufacturer or the adaptive medical equipment dealer. Sometimes, insurance companies have contracts with some manufacturers and not others. Accordingly, there could be problems with payment.

Before purchasing equipment, be sure you and your child can test it out on a trial basis. Also, make sure the dealer and/or clinician is willing to provide training and follow-up for parents, other key adults and the child. When ordering equipment from a specific manufacturer, deal with the manufacturer's authorized local supplier, as this will simplify your relationship with the company you choose.

Most manufacturers offer custom-made models—if your child needs one, make sure parts and repair are easily available. Make sure the product offers a warranty, and see if it can be repaired locally. Also, consider leasing or renting a system, especially if the child's condition is expected to change.

Be cautious about multi-purpose products (i.e., commode/shower chair/wheelchairs) that perform many functions but none as well as a product designed for a specific application.

Above all, ask questions—about anything that may come to mind. Here are some frequently voiced concerns:

- *Adaptability:* The seating/positioning system should fit perfectly at the first use, but will it be able to grow with your child? As your child's skills evolve, can the chair be adapted without costly new parts? Equipment can be expensive; consider the price spread out over years of use.

continued on page 50

139

Positioning & Seating Directory

Accu-Back
1475 E Del Amo Blvd
Carson, CA 90745
(800) 272-8888

Accumec
32 Race St
San Jose, CA 95126
(408) 294-3100

Adamin
39 Haven Ave
Bergenfield, NJ 07621
(800) 833-3725

adaptAbility
PO Box 515
Colchester, CT 06415-0515
(800) 243-9232

Adaptive Engineering Lab
4403 Russell Rd, Bldg 2A, Unit 3
Mukilteo, WA 98275-5018
(800) 327-6080

Adaptive Products
6938B N Raintree Dr
Milwaukee, WI 53223
(414) 353-9196

Alagold
1920 S Court St
PO Box 4959
Montgomery, AL 36103
(205) 834-6900

Alimed
297 High St
Dedham, MA 02026
(800) 225-2610

American Ergonomics
200 Gate Five Rd, Ste 215
Sausalito, CA 94965
(415) 332-5635

Apar
95 Rantoul St
Beverly, MA 01915
(508) 927-9234

Back Ease
PO Box 5283
Louisville, KY 40205
(502) 451-0394

Backsaver Products
53 Jeffrey Ave
Holliston, MA 01746
(617) 429-5940

Bailey Manufacturing
118 Lee St
Lodi, OH 44254
(800) 321-8372

Bauerfeind USA
1590 N Roberts Rd #J14
Kennesaw, GA 30144-3679
(800) 423-3405

Bell-Horn
451 N 3rd St
PO Box 3408
Philadelphia, PA 19123
(800) 523-4518

Bodycare
315 Gilmer Ferry Rd
Ball Ground, GA 30107
(800) 858-9888

Bodyline Comfort Systems
3730 Kori Rd
Jacksonville, FL 32257
(800) 874-7715

C F Wood Industries
7021 W Augusta Ave, Ste 108
Glendale, AZ 85303
(602) 939-0570

Canadian Posture & Seating Center
Invacare, 15 Howard Pl
PO Box 1473, Station C
Kitchener, Ontario N2G 4P2
(519) 743-8224

Canadian Wheelchair Mfg Ltd
1312 Blundell Rd
Mississauga, Ontario L4Y 1M5
(416) 275-3960

Canyon Products
10173 Croydon Way
Sacramento, CA 95827
(800) 221-5499

Cascade Designs
4000 1st Ave S
Seattle, WA 98134
(800) 527-1527

CHS International
PO Box 21067
550 39th Ave NE
Columbia Heights, MN 55421
(800) 878-4550

Columbia Medical Mfg
PO Box 633
Pacific Palisades, CA 90272
(310) 454-6612
See our ads on pgs 27,29.

Comfort Med
609 Interchange Dr SW
Atlanta, GA 30336-1603
(800) 527-3626

Comfy Back/Evans
1611 Lincoln Blvd, PO Box 988
Venice, CA 90294
(800) 272-6639

Commander Omni Company
PO Box 246
Garden City, NY 11530
(800) 645-4704

Community Playthings/Rifton Equipment
Rt 213, PO Box 901
Rifton, NY 12471-0901
(800) 777-4244

Consumer Care Products
PO Box 684, 810 N Water St
Sheboygan, WI 53082
(414) 459-8353

The following list of seating/positioning equipment manufacturers was provided by ABLEDATA, an Assistive Technology database located at the National Rehabilitation Information Center (NARIC). For more information, contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216.

Contour Fabricators
PO Box 56, 4100 E Baldwin Rd
Grand Blanc, MI 48439
(313) 695-2910

Convaid Products
PO Box 2458
Rancho Palos Verdes, CA 90274
(310) 539-6814
See our ad on pg 14.

Crazy Creek Products
1401 S Broadway
PO Box 1050
Red Lodge, MT 59068
(406) 446-3446

Creative Rehab Equipment
609 NE Schuyler St
Portland, OR 97212
(800) 547-4611

Custom Rehab Equipment
PO Box 601
Powassan, Ontario P0H 1Z0
(705) 729-2072

Danmar Products
221 Jackson Industrial Dr
Ann Arbor, MI 48103
(800) 783-1998

Dermacare
7651 National Turnpike
Louisville, KY 40214
(800) 626-4550

Double K Products
915 W Lehigh Ave, PO Box 1087
Englewood, CO 80150
(303) 781-4019

Duro Med Industries
301 Lodi St
Hackensack, NJ 07602
(800) 526-4753

Dynamic Systems
Rt 2, Box 182B
Leicester, NC 28748
(704) 683-3523

Elyon
PO Box 20548
Bradenton, FL 34203
(800) 435-5484

Embracing Concepts
40 Humboldt St
Rochester, NY 14609
(800) 962- 5542

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681
See our ad on pg 57.

ERGO-EEZE
PO Box 82263
Phoenix, AZ 85071-2263
(602) 789-0877

ETAC USA
2325 Parklawn Dr, Ste P
Waukesha, WI 53186
(800) 678-3822

Everest and Jennings
1100 Corporate Sq Dr
St Louis, MO 63132-2908
(800) 235-4661

Flaghouse
150 North MacQuesten Pkwy
Mt. Vernon, NY 10011
(800) 221-5185
See our ad on pg 60.

Foam Products
4747 Bronx Blvd
Bronx, NY 10470
(800) 283-4362

Folio Products
1341 Sherman Dr, Unit A
Longmont, CO 80501
(800) 356-4125

Frank Stubbs
4518 Vanowen St
Burbank, CA 91505
(800) 223-1713

Fred Sammons Co
Box 32
Brookfield, IL 60513-0032
(800) 323-5547

Freedom Designs
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551

G E Miller
540 Nepperhan Ave
Yonkers, NY 10701
(800) 431-2924

Gendron
400 E Lugbill Rd, PO Box 197
Archbold, OH 43502
(800) 537-2521

George H Snyder Enterprises
5809 NE 21st Ave
Fort Lauderdale, FL 33308
(305) 772-6526

Golden Fleece International
14240 60th St N
Clearwater, FL 34620
(800) 562-7326

Golden Technologies
159 Penn Ave
Exeter, PA 18643
(800) 624-6374

Grandmar
1311 63rd St
Emeryville, CA 94608
(415) 428-0441

Gunnell
8440 State St
Millington, MI 48746
(800) 551-0055

Hartwell Medical
6352 Corte Del Abeto #J
Carlsbad, CA 92009-1408
(800) 633-5900

Hausmann Industries
130 Union St
Northvale, NJ 07647
(800) 526-0289

Hermell Products
23 Britton Dr, Box 7345
Bloomfield, CT 06002
(800) 233-2342

Homedics
6841 N Rochester Rd, Bldg H
Rochester Hills, MI 48306
(800) 333-8282

IDC Tectonics Ltd
PO Box 2104 Station B
St Catherines, Ontario L2M 6P5
(416) 684-0609

Independent Specialty
PO Box 39
Middle Haddam, CT 06456
(203) 267-9792

Invacare
PO Box 4028, 899 Cleveland St
Elyria, OH 44036-2125
(800) 333-6900

J A Preston
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
See our ad on the back cover.

J C & Co
6670 30th Ave
Remus, MI 49340
(517) 967-3418

J T Posey
5635 Peck Rd
Arcadia, CA 91006
(800) 423-4292

Jaeco Orthopedic Specialties
214 Drexel, PO Box 75
Hot Springs, AR 71901
(501) 623-5944

Janice Invalid Security Alert Systems
7218 Lanai
Long Beach, CA 90808
(310) 421-3367

Jay Medical Ltd
PO Box 18656
Boulder, CO 80308-8656
(800) 648-8282
See our ad on pg 3.

Kaye Products
1010 E Pettigrew St
Durham, NC 27701-4299
(919) 732-6444

Kendall-Futuro
1 Riverfront Pl, Ste 900
Newport, KY 41071
(800) 933-0210

Kennedy Krieger Institute
707 N Broadway
Batimore, MD 21205
(410) 550-9000
See our ad on pg 9.

Kid Kart
126 Rosebud St, #1
Belgrade, MT 59714
(406) 388-1080

Labac Systems
8955 S Ridgeline Blvd, Ste A
Highlands Ranch, CO 80126
(800) 445-4402

Laurel Designs
5 Laurel Ave
Belvedere, CA 94920
(415) 435-1891

Les Equipements Adaptes/Physipro
783 rue Longpre
Sherbrooke, Quebec J1G 4S8
(819) 823-2252

Lossing Orthopedic
777 Harding St NE, Ste M-4
PO Box 18298
Minneapolis, MN 55418
(612) 331-3985

Loyal LaPlante Supply
6702 E 11th St
Tulsa, OK 74112
(918) 835-6381

Lumex
100 Spence St
Bay Shore, NY 11706-2290
(800) 645-5272

Luxury Liners
14747 Artesia Blvd, Bldg D
La Mirada, CA 90638
(800) 247-4203

Maddak
6 Industrial Rd
Pequannock, NJ 07440
(800) 443-4926

Maramed Precision
2480 W 82nd St
Hialeah, FL 33016
(305) 823-8300

McCarty's Sacro-Ease
3329 Industrial Ave
Coeur d'Alene, ID 83814
(800) 635-3557

Medical Line Warehouse
6130 Clark Ctr Ave #103
Sarasota, FL 34238
(800) 247-2256

Midwest Contracting & Manufacturing
E Highway 40, PO Box 175,
WaKeeney, KS 67672
(913) 743-5460

Millers Special Products
284 E Market St
Akron, OH 44308
(800) 621-2630

Modern Healthcare Concepts
2303 1st St, Holiday Garden Estate
Newport & Richey, FL 34652
(813) 846-0194

Modular Medical
1513 Olmsted Ave
Bronx, NY 10462
(212) 829-2626

Motor Development
9340 Buell St
Downey, CA 90241
(213) 862-6741

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93060
(805) 525-7165
See our ad on pg 48.

NADA CHAIR
783 Harding St NE
Minneapolis, MN 55413-2813
(800) 722-2587

New Directions International
9 Butternut—C
Orchard Park, NY 14127
(716) 662-4917

OPS
14228 Cherry Ln Ct
Laurel, MD 20707
(301) 470-3344

OBUS Forme, Ltd
550 Hopewell Ave
Toronto, ONT M6E 2S6
(800) 361-1378

Ohio Medical Instrument Company
3924 Virginia Ave
Cincinnati, OH 45227
(513) 561-2241

Olympic Medical
5900 1st Avenue S
Seattle, WA 98108-3249
(800) 426-0353

Ortho Concepts
285 Alpha Park
Highland Heights, OH 44143
(216) 449-8222

Ortho-Kinetics
W220 N507 Springdale Rd
PO Box 1647
Waukesha, WI 53187-1647
(800) 588-7786

Orthopedic Physical Therapy Products (OPTP)
PO Box 47009, 3700 Annapolis Ln
Minneapolis, MN 55447-0009
(800) 367-7393

Orthopedic Products
10381 W Jefferson Blvd
Culver City, CA 90232
(310) 202-7766

Ostergaard Enterprises
PO Box 15268
Fresno, CA 93702
(209) 275-4695

Otto Bock
3000 Xenium Ln N
Minneapolis, MN 55441
(800) 328-4058

Parker Sales
285 N Amphlett Blvd
San Mateo, CA 94401
(415) 344-4550

PCP Champion
PO Box 125
Ripley, OH 45167-0125
(800) 888-0867

Pillow Place
1940 Moores Mill Rd NW
Atlanta, GA 30318
(800) 832-2022

Pin Dot Products
6001 Gross Point Rd
Niles, IL 60648-4027
(800) 451-3553

Posture Support Mfg
5907 Harper Rd
Solon, OH 44139
(216) 248-9086

Prospect Designs
11 Prospect St
New Hartford, CT 06057
(203) 379-7858

Pyramid Rehabilitation
4993 Southern Ave
Memphis, TN 38117
(800) 962-7615

Quickie Designs
2842 Business Pk
Fresno, CA 93727
(800) 456-8168

R & H Adaptive Equipment
PO Box 175
Thompson, IA 50478
(800) 255-6956

Raymo Products
212 S Blake
PO Box 248
Olathe, KS 66061
(913) 782-1515

RE TEC—Rehabilitation Technologies
121 Haven Ridge
Peachtree City, GA 30269
(404) 351-4486

Rehab Centre for Children
633 Wellington Cres
Winnipeg, Manitoba R3M 0A8
(204) 452-4311

Rehab Equipment Systems
202 Westlake Ave N
Seattle, WA 98109
(206) 624-3123

141

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or Product & Service listing or refer to the Directory of Advertisers.

2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.

3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.

4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

A FULLY INTEGRATED SYSTEM WITH POSTURAL SUPPORT, MOBILITY, GROWTH POTENTIAL AND TRANSPORTABILITY!

THE MULHOLLAND GROWTH GUIDANCE SYSTEM™

- Interactive with a Child's Therapy Objectives
- Step Release Tilt in Space
- Van/Bus and Car Seat Transportable
- Long Term Growth Capability

Designs for the Development of Functional Skills

Mulholland
Positioning Systems Inc.

P. O. Box 391
Santa Paula, CA 93061
(800) 543-4769

Circle #54

DIRECTORY OF ADVERTISERS

Circle #	Advertiser	Page #
	Abilities Expo	54
#9	AccessAble Environments	10
#150	Aquatic Therapy	37
#7	BHC JA Preston	back cover
#6	Berkshire Meadows	17
#158	Braun	40
#90	Chrysler	inside back cover
#11, #13	Columbia Medical	27, 29
#16	Convaid	14
#17	Crotched Mountain	49
#151	Crystal Springs	37
#19	Devereux	5
#152	Edit Point	29
#25	Equipment Shop	57
#26	Estate Planning	11
	Exceptional Parent Library	62
#27	Evergreen	17
#29	Flaghouse	60
#30	Ford	13
#153	Friendly Earth	29
#154	Hacienda de los Angeles	38
#37	HDIS	57
#39	HMS School	52
#36	Haverich Ortho-Sport, Inc.	7
#38	Heartspring	12
#156	Human Policy	44
#43	Innovative Products	34
#44	Jay Medical	3
#45	Kennedy Krieger	9
#136	Marble Soft	15
#54	Mulholland	48
#159	National Mobility	43
#56	Nu-Tech Health	15
#155	Parent Care	58
#60	Phonic Ear	52
#103	Rhamdec	26
#157	ROHO, Inc.	20
#75	St. John's Villa	17
#68	Sentient Systems	58
#69	Snug Seat	inside front cover
#71	Special Design	15
#78	Stroller Pack	44
#86	Woodbury Products	34

EXCEPTIONAL PARENT

FACILITATING YOUR CHILD WITH A DISABILITY

Vice President Advertising Sales
Kerry J. Cannon
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/
Fax (201) 489-1240

Sales Representatives

Greater New York - Joni Jones
Phone (516) 944-8068/Fax (516) 944-2739

New Jersey, Schools, Camps, Residences, Classified & Special Sales - Barbara Nastro
Phone (201) 680-4874/Fax (201) 680-8355

New England, Upstate NY and East Canada - Barbara H. Arnold
Phone (617) 259-9207/Fax (617) 259-9883

MidAtlantic (DE, DC, MD, PA, VA, WV) - J. Ronald Doran
Phone (908) 741-6869/Fax (908) 530-8216

Southeast (AL, FL, GA, MS, NC, SC, TN) - William Middleton
Phone (404) 973-9190/Fax (404) 859-0051

Midwest (IN, KY, KS, MN, ND, OH, SD, UT, CO) - Anthony Arnone
Phone & Fax (708) 428-5162

Midwest (IL, IO, NE, MO, MI) - John Maisel
Phone (708) 416-0780/Fax (708) 416-0793

Southwest (AZ, NM, TX, OK, LA, AR) - Sherylen Young
Phone (602) 991-2889/Fax (602) 596-4026

West Coast (So CA, NV) - Richard Ayer
Phone (714) 366-9089/Fax (714) 366-9289

West Coast (No CA, OR, WA, HI, BC) - William Hague
Phone (206) 858-7575/Fax (206) 858-7576

Ad Traffic Manager
Stefanie Ferrante
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/Fax (201) 489-1240

BPA International Consumer Magazine Membership Applied for August 1993.

Subscriptions:
Exceptional Parent
P.O. Box 3000, Dept. EP, Denville, NJ 07834
(800) 247-8080 (New subscriptions ONLY)
(800) 562-1973 (Customer Service)

Exceptional Parent magazine has excepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

Confidence, Independence, Success...

The Crotched Mountain Rehabilitation Center and School offers innovative academic, therapeutic, residential, and medical services designed to maximize the educational potential of physically and developmentally challenged children and young adults with:

• Head Injury • Cerebral Palsy • Spina Bifida
• Autism • Down's Syndrome • Developmental, Behavioral, Emotional and Neurological Disorders
• Fetal Substance Exposure

The CMRC program includes:

• Fully Accredited Preparatory School Curriculum
• Modern Residential Group Homes
• Licensed Nursing Facility • Day Students
• Total Communications Center
• Fully Adaptive and Accessible Sports Facility

CROTCHED MOUNTAIN
REHABILITATION CENTER INC

A subsidiary of the Crotched Mountain Foundation
1 Verney Drive Greenfield, New Hampshire 03047 (603) 547-3311

Circle #17

Rehabilitation Technical Components—RTC
PO Box 784, 1256 Liberty Ave
Hillside, NJ 07205
(908) 687-8275

Relaxo Bak
PO Box 812, 319 E California St
Gainesville, TX 76240
(800) 527-5496

Rhamdec
476 Ellis St
Mountain View, CA 94043-2240
(800) 428-0620
See our ad on pg 26.

Rinz L O Pillow
340 W Maplehurst
Ferndale, MI 48220
(313) 548-3993

Roho
PO Box 658
Belleville, IL 62222
(800) 851-3449

RolControl Product
6750 Worth Way
Camarillo, CA 93012
(805) 386-4191

S&S Manufacturing Import/Export
PO Box 2485
York, PA 17405
(717) 843-2745

Scott Specialties
PO Box 129
Belleville, KS 66935
(800) 255-7136

Snug Seat
PO Box 1739
Matthews, NC 28106-1739
(800) 336-7684
See our ad on inside front cover.

So Cal Orthopedics
1941 Miraloma Ave
Placentia, CA 92670
(714) 524-1980

Sorbothane
2144 State Rt 59
PO Box 178
Kent, OH 44240
(216) 678-9444

Special Designs
PO Box 30
Gillette, NJ 07933
(908) 464-8825
See our ad on pg 15.

Special Health Systems Ltd
90 Engelhard Dr
Aurora, Ontario L4G 3V2
(800) 263-2223

Tallahassee Therapeutic Equipment
9601 Miccosukee Rd, Lot 13
Tallahassee, FL 32308-9609
(800) 476-0487

Tetra Development Society
Plaza of Nations
Box 27, 770 Pacific Blvd S
Vancouver, BC V6B 5E7
(604) 688-6464

Thera P Cushion
210 S 8th St
Lewiston, NY 14092
(416) 784-3727

Theradapt Products
17 W 163 Oak Ln
Bensenville, IL 60106
(708) 834-2461

Therafin
PO Box 848
Mokena, IL 60448-0848
(800) 843-7234

Therapeutic Creations
544 Ygnacio Valley Rd #A-261
Walnut Creek, CA 94596,
(415) 930-3460

Therapeutic Health & Equipment Specialists
14000 NW 1st Ave
N Miami, FL 33168
(305) 961-5115

Thompson Medical Specialties
4301 Bryant Ave S
Minneapolis, MN 55409
(800) 777-4949

Toys For Special Children
385 Warburton Ave
Hastings-On-Hudson, NY 10706
(800) TEC-TOYS

Trujillo Industries
8038 Allport Ave
Santa Fe Springs, CA 90670
(213) 696-0539

Tumble Forms by Preston
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277

Uni Patch
PO Box 271
Wabasha, MN 55981-0271
(800) 328-9454

Variety Ability Systems
3701 Danforth Ave
Scarbrough, ONT M1N 2G2
(416) 698-1415

Velcro USA
406 Brown Ave
Manchester, NH 03108-5218
(800) 225-2610

Vesture
PO Box 791, 202 Commerce Pl
Randleman, NC 27317
(800) 462-4201

Wheel Ring
199 Forest St
Manchester, CT 06040
(203) 647-8596

Whitmyer Biomechanix
848 Blountstown Highway, Ste H
Tallahassee, FL 32304
(904) 575-5510

Wings of Vocational Guidance Services
2239 E 55th St
Cleveland, OH 44103
(216) 431-7800

WR Breen Holdings Ltd
1245A Kamato Rd
Mississauga, ON L4W 2M2
(416) 602-0880

XL Wheelchairs
4950-D Cohasset Stage Rd
Chico, CA 95926
(800) 356-3554

Zackback International
PO Box 9100
Rochester, MN 55903
(507) 281-7928

Purchasing Seating Equipment Tips for Parents

continued from page 45

- *Stability:* When the system is designed to attach to a wheeled base, does it attach easily? Is it stable and secure when the child is seated? If there are wheels, check the brakes/wheel locks carefully. Be wary of suction cups on bath supports—they have the potential to slip.
- *Ease of Operation:* Other people will need to work with the child's system. Will friends, teachers and baby-sitters be able to understand how it works? Check the seat belt/restraint buckles. Do they pinch? Can they adjust for differing thicknesses of clothing? Is there enough padding?
- *Portability:* Can your child be safely transported in the system?
- *Upkeep:* Can your system be easily cleaned? Is it waterproof? If your child is incontinent, request a waterproof cover over the area that needs protection. Are the fabrics machine washable/dryable? Do they feel good in hot or cold weather?
- *Aesthetics:* Go for bright, bold colors. Drab colors can be dispiriting to your child's self-esteem. When choosing, however, consider function first.

Resources

Thanks to the following seating/positioning experts for their contributions: Allen Siekman, Director of Seating & Positioning, Avanti by Invacare, Elyria, OH; Michael Caan, Ph.D., President, Columbia Medical Mfg., Pacific Palisades, CA; Terrand B. Grall, Ph.D., President, Consumer Care Products, Inc., Sheboygan, WI; Dave Hancock, Consultant, Flaghouse, Inc., Mount Vernon, NY; Susan Harryman, Director of Physical Therapy, Kennedy Krieger Institute, Baltimore, MD; Catherine Mulholland, Occupational Therapist, Mulholland Positioning Systems, Inc., Santa Paula, CA; Simon Margolis, Director of Seating and Wheeled Mobility Services, Otto Bock Ortho-pedic Industry, Inc., Minneapolis, MN; Sue Garvin, Senior Product Manager, Preston, Jackson, MI. ■

A.B.

144

Marketplace

Catalogs

Antoni Toys and Products
232 SE Oak St Suite 103
Portland, OR 97214
(800) 826-8664/(503) 233-1660
Assortment of colorful toys, one piece underwear, hand-made dolls, educational books, diapers and more! Call toll free for catalog.

Cribs & Youth Beds

HARD Manufacturing Co.,Inc
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Dowd Rental & Sales
100 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been servicing the area since 1930. For personal service and quality equipment and further information call Dowd Rental & Sales, Inc.

Rehabco®
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in childrens mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Oklahoma

Loyal LaPlante Supply Co.
6702 E. 11th St.
Tulsa, OK 74112
(918) 835-6381
Custom seating. Check Marc certified repairs. Authorized Check Marc Repair Center. We carry most products & advertised in this magazine.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800)242-2460
ATTENDS YOUTH BRIEFS fits children 35-75 lbs. $51.95/cs (96). Free Delivery. Also - Depend, Serenity, other items. Manufacturer's coupons accepted. FREE CATALOG!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Monitoring Systems

Care Electronics
5741 Araphoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog.

Resources/Special Needs

LINCS-BBS C/O PHP,
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Sports & Recreation

KID-KART
126 Rosebud, Ste #1
Belgrade, MT 59714
(800) 388-5278
The new **Kid-EZ3 Tilt/Recline Push Wheelchair** provides over 5 years of growth and offers precision positioning for children of all disabilities. The Kid-EZ POSITIONING SEAT transfers easily from the wheelchair to a high chair base and other convenient platforms. For further information, call **Kid Kart, Inc.** at 1-800-388-5278.

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

Florida

Action Mobility
1925 10th Ave. No.
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 in FL
Full or Mini-Van modifications. Scooter & wheelchair lifts, lifts, drop floor, raised roof, lockdowns, driving equipment. Install, customize, repair. All mfgs.

Georgia

DuraMed Driving Systems, Inc.
1543 15th Street
Augusta, GA 30901
(800) 637-1378
Custom driving systems, whlchr, scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Indiana

Forward Motions, Inc.
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Kentucky

Forward Motions, Inc.
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New Jersey

Arcola Mobility
51 Kero Road
Carlstadt, NJ 07072
(201) 507-8500/(800)ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

New York

Barrier Free Systems, Inc.
165 Freeman's Bridge Road
Scotia, NY 12302
(518) 346-4169
We sell and install equipment in the aid of transportation for the physically challenged. For more information, give us a call!

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

Ohio

Forward Motions, Inc.
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

TRI-STATE MOBILITY
Canton, OH (800) 343-3150
Toledo, OH (800) 345-3150
One of the largest inventories of used handicapped vans. Nationwide delivery available on request. Dealer for all major mobility equipment. NMEDA Member - Quad specialists.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

South Carolina

DuraMed Driving Systems, Inc.
1543 15th Street
Augusta, GA 30901
(800) 637-1378
Custom driving systems, whichr, scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Texas

Advanced Conversions
2105 N. Beach Street.
Fort Worth, TX 76111
(817) 834-1003
Guy Tucker, President. Adaptive vehicle modifications. NMEDA member. 6 yrs. in business. Buy-sell-trade-lease new and used equipment. Wheelchair/scooter lifts. 24 hour services. Sale/Service: Ricon, Bruno, Mobil-Tech, EMC, EZ Lock, MPD, MPS, Kneel KAR, Care Concepts.

Wheelchair Accessible Homes

MD News
P.O. Box 12
Glenmore, PA 19343
(610)942-3266
Buy, Sell or Rent. Monthly Newsletter lists houses and apartments for Sale or Rent. Free Copy. Advertise Free.

Books, Audio/Video & Educational Material

Books for Parents & Professionals

Turtle Books: provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to **Jason & Nordic Publishers,** P.O. Box 441 Hollidayburg, PA 16648 or FAX (814) 696-4250

Free–The NEW Special Needs Project Book Catalog. The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. **Special Needs Project,** 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection features a collection of valuable books for parents on Down syndrome, CP, autism, Tourette syndrome, mental retardation, special education and more. **Woodbine House** Contact: 5615 Fishers Lane, Rockville, MD 20852, (800)843-7323

Educational materials

Attainment Company's 1994 Product Guide is out! Call or write for your **free copy** and see our latest products: New Software, The Pocket Talker, Board Games, Money Skills Materials. **Attainment Company,** P.O. Box 930160, Verona, WI 53593-0160, (800)327-4269

Videotapes

Interax Video Sign Language Course. Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

HMS School

For Children With Cerebral Palsy

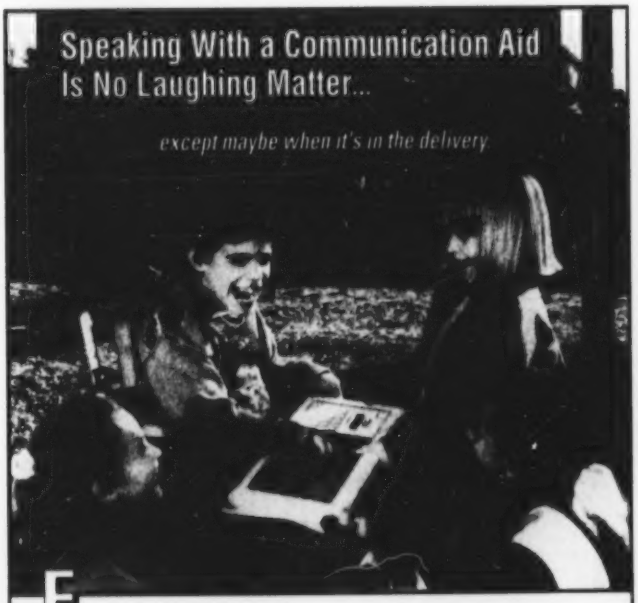
Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- *Physical Therapy*
- *Occupational Therapy*
- *Speech and Language Therapy*
- *Communication Aids*
- *Special Education*
- *Music Therapy*
- *Special Medical Attention*
- *Adapted Recreational Activities*

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle #39



For telling a joke, saying "I love you", or just expressing a need, **PALLS®** is the only device that offers three flexible programs for any level of communication.

So if you know someone who may have a few good jokes to tell, give us a call–you'd be surprised at what we can do with the delivery.

(800) 227-0735 U.S. (800) 263-8700 Canada

Phonic Ear
Innovative Communication Technologies

Circle #60

ALD—Balancing Hope Against Reality

by Hugo W. Moser

Hugo W. Moser, M.D.

My wife Ann and I have been concerned with Adrenoleukodystrophy (ALD) since 1978 and now work on little else. The current situation with ALD is a perfect example of the hopes and controversies that arise when as yet unproved, still imperfect therapies emerge for a previously untreatable disorder.

The last 15 years have seen a number of exciting developments in diagnosis, prenatal screening and carrier detection. And recently, the ALD gene itself has been isolated. Wholeheartedly supporting our efforts has been a fine and extremely valuable parents' organization—the United Leukodystrophy Foundation (ULF)—now in its twelfth year. Parents value all the advances that have been made, but in the absence of effective therapy, these advances are "flat" and unsatisfactory.

In search of therapies

During our 12-year association with the ULF, we have come to realize that if we lose credibility with parents, we lose everything. We must always inform families of the facts, as we understand them at any given moment. The facts can be painful. Sometimes it is impossible to tell the truth to families without shattering their hopes and creating despair. To help reduce such despair and in a genuine effort to advance the capacity to treat, we offer all patients the chance to enroll in therapeutic protocols that have a rational basis and are free of inappropriate risk. These experimental treatments are monitored by an expert Institutional Review Board and have the full knowledge and endorsement of the ULF.

Our primary and increasingly passionate efforts are directed toward the search for an effective therapy for ALD. We are deeply concerned and frustrated that treatments are still so imperfect. Current hopes rest with dietary therapy, bone marrow transplantation and—in the more distant future—gene therapy. In addition, we are studying families in which some members are affected by the rapidly progressive form of the childhood disease, while their affected brothers, uncles or grandfathers have only the milder, adult form. Understanding the ways in which the rapidly progressive form of the illness develops may lead to the ability to alter these mechanisms.

Success of current therapies

Though "Lorenzo's Oil" was a good and highly rational idea, research has shown that it is of little or no benefit to patients who already have significant neurological problems by the time they start this therapy. However, our recent data suggest that "Lorenzo's Oil" may help to prevent the onset of neurological problems if it is started before such symptoms are present.

Bone marrow transplantation is a promising therapy for ALD—but only when performed early in the course of the illness using a well-matched marrow donor. Gene therapy is a great hope also, but its use is a number of years away.

The rapid progression of the most serious and common form of ALD—the childhood cerebral form—is caused by a brain inflammatory response. At this moment, we do not have a therapy for this form of the disease. We are about to initiate an entirely new treatment, however. If successful, this therapy will work by suppressing the inflammatory response of the brain. ■

Hugo W. Moser, M.D., is Director of the Mental Retardation Research Center at the Kennedy Krieger Institute in Baltimore, Maryland, and Professor of Neurology and Pediatrics at the Johns Hopkins University School of Medicine.

Tuberous Sclerosis Gene Identified

Researchers have identified one of two genes for tuberous sclerosis complex (TSC). The gene for TSC2 on chromosome sixteen has been found; the search for the gene for TSC1 on chromosome nine continues. TSC is an autosomal dominant genetic disease affecting one in 5,000–6,000 live births. As many as 60 percent of new TSC cases are new mutations. Progress in gene identification may lead to the availability of an accurate screening and diagnostic genetic test for TSC in the next few years. For more information or to volunteer to serve as a research participant, contact the National Tuberous Sclerosis Association, 8000 Corporate Dr., Ste. 120, Landover, MD 20785, (800) 225-6872. ■

Car Seat Warning

The National Highway Traffic Safety Administration (NHTSA) has asked us to warn parents that a rear-facing child safety seat should never be used in the front seat of an air-bag-equipped vehicle. An inflating air bag could strike the child seat with enough force to cause serious head and chest injuries. A vehicle's back seat is the safest place for any child safety seat. For more information, call NHTSA's Auto Safety Hotline—(800) 424-9393.

REACH FOR THE STARS

ABILITIES EXPO '94

New Jersey & California

The #1 Show of Products and Services for People with Disabilities

Opportunities to try and buy on the Show floor

One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-Wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

Longest running show of its kind in the U.S.

Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO in a city near you:

ABILITIES EXPO EAST
Edison, NJ
Raritan Expo Center
April 15–17, 1994

ABILITIES EXPO WEST
Anaheim, CA
Anaheim Convention Center
May 20–22, 1994

For more information on attending please call 203/256-4700.

SAVE ONE DOLLAR • SAVE ONE DOLLAR

ABILITIES EXPO

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. *Name and address must be completed to validate coupon.*

Name _____

Address _____

City _____ ***State*** _____ ***Zip*** _____

Telephone (____) _____ – _____ ***CA/NJ94 J***

ABILITIES EXPO

New Jersey – Produced by Expocon Management Associates, Inc. and RCW Productions Inc. – *California*

Annual Income Tax Guide

by L. Mark Russell

It's everyone's favorite time of the year once more—time to think about taxes! As you no doubt know, tax law is very complicated. It is important that you understand it, however, so you can take advantage of all the deductions and credits to which you are entitled.

Unclaimed deductions and credits cost families hundreds, sometimes thousands, of dollars every year. This is especially true of families who have a member with a disability. These families are often entitled to deductions and credits which are unavailable to others. Sometimes even accountants are unaware of the possibilities. This article will summarize items that are of particular interest to families with members who have disabilities.

> *"Families who have a member with a disability are often entitled to deductions and credits which are unavailable to others."*

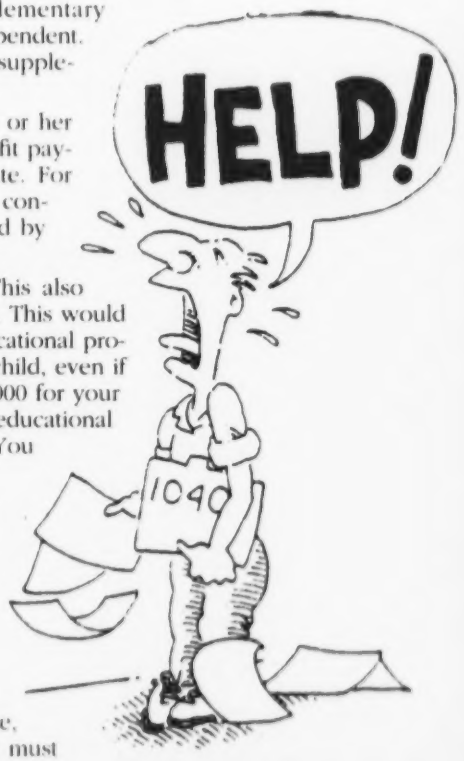
Exemptions For Dependents

You can take a deduction of $2,350 for yourself, and for each person who is your dependent. This is true whether or not the dependent has a disability. For example, if you have two dependents, and you and your spouse file a joint tax return, you will be entitled to a deduction of $9,400 ($2,350 x 4).

In most cases, it is relatively simple to determine whether a person is a dependent. If you provide more than half the person's support and the person is related to you, the deduction is generally permissible. You determine whether you have provided more than half the dependent's support by comparing the amount you contributed to the entire amount of support received from all sources, including the dependent's own funds and government funds. Support is not limited to necessities. Support includes money spent to provide food, shelter, clothing, education and medical and dental care; but it also covers money spent on recreation, allowances, gifts and vacations.

Medical insurance premiums—including premiums you pay for supplementary Medicare coverage—are included in the total support you provide for the dependent. Medical insurance benefits the child receives, however, including basic and supplementary Medicare benefits, are not considered support.

If a dependent receives Social Security benefits and uses them toward his or her own support, this is considered support provided by the dependent. State benefit payments based on need generally are considered support provided by the state. For example, Aid to Families with Dependent Children (AFDC) payments are not considered support provided by the parent. They are considered support provided by the state.



Scholarships received by your dependent are not considered support. This also includes the value of education, room and board provided for your dependent. This would also apply to a scholarship for a child with mental retardation to attend an educational program if the program certifies that it is making an effort to educate or train the child, even if the payments are made by the state. For example, suppose the state pays $30,000 for your daughter's room, board and tuition at a residential facility that qualifies as an educational organization. In the same year, you provide $5,000 as her only other support. You may still claim her as a dependent because the scholarship is not included.

You cannot take an exemption for your child if he or she was 19 or older at the end of the year and had a gross income during the year of more than $2,350. If your child is a student under the age of 24, this "gross income test" does not apply. If you claim your child as a dependent, however, your child cannot claim a personal exemption on his or her own return.

Limitations on the Medical Expenses Deduction

You are entitled to an income tax deduction for medical expenses for yourself and for your dependents. For this deduction, a dependent is defined as above, except that the "gross income test" does not have to be satisfied. The person must

have qualified as your dependent when the medical services were provided or when the bill was actually paid.

A number of hurdles must be passed before medical expenses may be deducted. First, medical expenses are deductible only to the extent that they exceed seven-and-a-half percent of your adjusted gross income. For example, if your adjusted gross income for the year is $30,000, you will only be able to deduct expenses in excess of $2,250 (7.5% of $30,000).

Second, medical expenses may be deducted only if you itemize deductions. Taxpayers who do not have significant itemized deductions are entitled to take the standard deduction instead. The standard deduction is equal to $6,200 for married taxpayers filing joint returns and $3,700 for singles. If you take the standard deduction, you will not be entitled to deduct medical expenses. Similarly, you cannot take the medical expense deduction if you use Form 1040A or 1040 EZ, because you must figure the deduction on Schedule A, Form 1040—commonly called the "long form."

> *"The definition of medical expenses is construed very broadly so that many expenses that you may not think are qualifying are deductible."*

Third, you cannot deduct expenses that are paid by insurance. You can deduct expenses that you pay (and that are not reimbursed by your insurance company).

As a result of these limitations, the medical expense deduction may not be available to many families. However, the deduction can be very valuable for many others.

Defining "Medical Expenses"

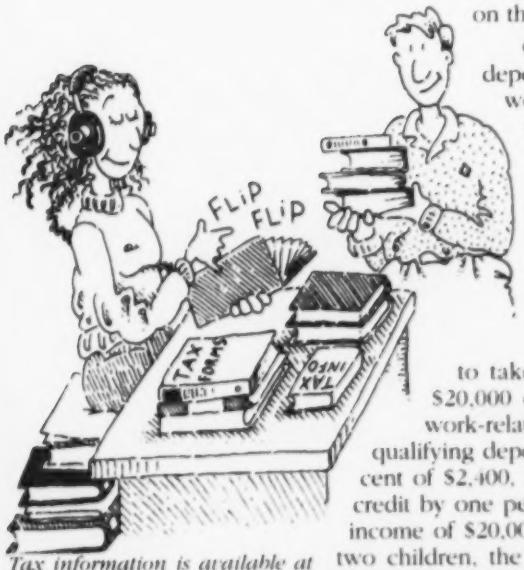
According to the IRS, a deductible medical expense includes "any amount paid for the diagnosis, cure, mitigation, treatment, or prevention of disease; or for the purpose of affecting any structure or function of the body; and transportation cost on a trip primarily for and essential to medical care." This definition is construed very broadly so that many expenses that you may not think are qualifying are deductible medical expenses. You can use the worksheet on page 57 to keep track of your deductible medical expenses.

Avoiding IRS Reviews

Many parents with children who have disabilities deduct larger amounts of medical expenses than other families. As a result, they may draw special notice from the Internal Revenue Service. The IRS computer may single out taxpayers who deduct proportionately higher medical expenses in relation to their income level for review. To reduce the IRS's suspicions, you can describe your child's disability in a letter written by yourself or your child's doctor and attach it to your tax return. In case your tax return is reviewed, however, store your receipts and canceled checks carefully. One key to good tax planning is good record keeping.

Tax Credits

In addition to the tax deductions described above, a variety of tax credits also may be available to you. Tax credits can be even more valuable than tax deductions because they are subtracted directly from taxes due. For example, if you are in a 28 percent income tax bracket, a $2000 deduction will reduce your taxable income by $2000. However, this represents a savings on your tax bill of only $560 (28% of $2000). A $2000 tax credit, on the other hand, reduces your tax bill by $2000.



Tax information is available at most local libraries

Child and Dependent Care Credit. If you pay someone to care for a dependent so that you and your spouse can work, attend school or look for work, you may be entitled to take the Child and Dependent Care Credit. If your adjusted gross income is $10,000 or less, your credit is generally equal to 30 percent of work-related child care expenses. The 30 percent figure is reduced by one percent for each $2,000 or part of $2,000 of adjusted gross income above $10,000 until the percentage is reduced to 20 percent for income above $28,000. The limit on work-related child-care expenses is $2,400 for one qualifying dependent and $4,800 for two or more dependents. The credit is computed on Form 2441 if you file Form 1040, or Schedule 2 if you use Form 1040A.

For example, suppose a widower pays a housekeeper $5,000 a year to take care of his home and his daughter while he is working. He earns $20,000 during the year. Even though he spent at least $5,000, the maximum work-related expenses he can claim are $2,400. This is because he has only one qualifying dependent, his daughter. Therefore, the largest credit he can claim is 25 percent of $2,400, or $600. (The 25 percent credit is calculated by reducing the 30 percent credit by one percent for every $2,000 of income above $10,000. Since the widower had income of $20,000, the 30 percent credit is reduced by five percent.) If the widower had two children, the credit would be 25 percent of $4,800, or $1,200. If the man's income exceeded $28,000, the credit would be 20 percent of qualifying expenses.

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: February 28, 1994

Expiration Date: May 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: February 28, 1994

Expiration Date: May 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

FREE!

Full-color Catalog & Attends coupon

Get our **FREE Full-color catalog** that shows **the wide variety of incontinence products we deliver right to your door at low buy-by-the case prices.** Along with our catalog you will receive a **coupon that entitles you to an Attends trial pack at a discounted price!** Select the products you need for your child today!

HDIS™

Home Delivery Incontinent Supplies Co., Inc.
P.O. Box 52039
St. Louis, MO 63136

Send in this coupon for a free catalog and Attends coupon, or call us toll-free at **1-800-538-1036**.

Name

Address

City, State, Zip

( )
Phone

Copyright HDIS, 1994 24/40

Circle #37

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

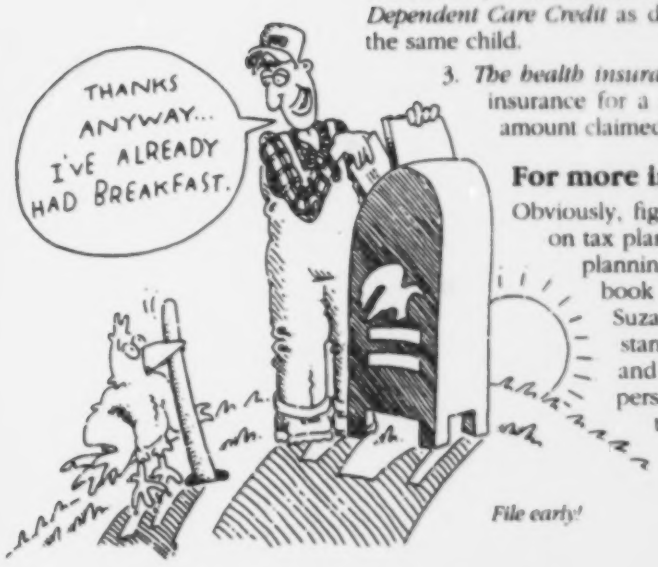
Circle #25

Medical Expenses Worksheet

1. **Transportation costs** for taking your child to special schools, institutions, hospitals, doctors, clinics, pharmacies, etc.
   - a. Mileage (9¢ per mile) or actual expenses (gas/oil)
   - b. Parking
   - c. Tolls
   - d. Cost of an attendant to accompany child
   - e. Cost of attendant to accompany child on school bus
2. **Medical Expenses** (standard)
3. **Hospital Expenses** (standard)
4. **Medicine**—Drugs and vitamins prescribed by a doctor only
5. **Special Education Expenses**
   - a. Tests and evaluations at special school
   - b. Special instruction in Braille, lip-reading, speech
   - c. Tutoring by a qualified teacher if recommended by a doctor
   - d. Room, board and tuition at residential facility if main reason for attending is to alleviate medical condition
6. **Sheltered Workshop Expenses**—payments to a sheltered workshop for the provision of services
7. **Special Equipment**
   - a. Any special equipment prescribed by a doctor. May include air conditioning, ramps, elevators, etc.
   - b. Repair of special equipment (including TDDs)
   - c. Closed-captioned television or decoder
8. **Attendant Care**
   - a. Nursing services
   - b. Meals for attendants
9. **Aids for Persons with Visual Impairments**
   - a. Audio tapes
   - b. Special typewriters
   - c. Special lenses or other visual aids
   - d. Cost and care of guide dogs
10. **Lifetime-Care Payments**—Non-refundable advance payments to a private institution to insure that they will care for your child in the future.
11. **Transitioning Expenses**—Costs involved in helping a person with mental retardation adjust to life in a community setting.
12. **Miscellaneous**
    - a. Expenses involved in providing "patterning exercises"
    - b. Disposable diapers for incontinent child or adult, if prescribed by a doctor
    - c. Special foods and beverages (e.g. formula for tube feeding)—Costs in excess of what would have been spent for "regular" food.
    - d. Dental care
    - e. Eyeglasses, contact lenses, eye examinations
    - f. Hearing aids, batteries, hearing evaluations
    - g. Wheelchairs, braces, other adaptive equipment
    - h. Birth control pills
    - i. Legal sterilization
    - j. Oxygen equipment and oxygen
    - k. Medical and hospital insurance premiums (see formula in tax form)
    - l. Social Security tax for worker providing medical services
    - m. Cost and care of dog or other animals used as aids to persons with disabilities
    - n. Legal abortion

Earned Income Credit. If your income is below $23,050 and you had a child with a disability living with you for at least 6 months during the year (or any minor child without a disability), you may be entitled to the Earned Income Credit. If the credit exceeds the amount of taxes owed, you can get a refund. You should use Schedule IC to claim the credit. The credit is equal to the sum of the following three components:

1. *The basic credit* is determined by multiplying your earned income by a percentage which varies, depending on the amount of your income and the number of qualifying dependents. The maximum credit is $1,434 if you have one qualifying child and $1,511 if you have more than one qualifying child.
2. *The young child credit* is available if you have a child who was under the age of one on December 31. The maximum credit is $388. However, if you are claiming the *Child and Dependent Care Credit* as described above, you cannot claim the *young child credit* for the same child.
3. *The health insurance credit* is available for premiums paid to provide health insurance for a qualifying dependent. The maximum credit is $465 and the amount claimed cannot also be claimed as a medical expense deduction.



File early!

For more information...

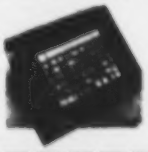
Obviously, figuring your taxes can be very complicated. More information on tax planning, as well as information relating to the important topic of planning for your child's life after your death, can be found in the book *Planning For The Future* by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph and Richard W. Fee. Easy to read and understand, the 400-page book is a comprehensive guide to the life- and estate-planning process, and contains all the information—personal care, financial and legal—that parents must consider as they plan for their children's lives after their own deaths. The book can be ordered from the Exceptional Parent Library, P.O. Box 8045, Brick, New Jersey 08723, 1-800-535-1910. The cost is $24.95, plus $3.50 shipping and handling. ■

You Asked DynaVox To Do Even More...

"I want to tell a story."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at 1-800-344-1778.



We Hear You.

TECHNOLOGY INC. Circle #68

"...non-profit partnership of parents and professionals dedicated to improving the newborn intensive care experience and future for babies, families and caregivers."

PARENT CARE INC.

10th National Conference
"Celebrate Our Commitment"
May 11-14, 1994
Salt Lake City, Utah

Speakers:
T. Berry Brazelton, M.D., pediatrician, researcher, author
Josef J. Reum, Deputy Director, Robert Wood Johnson
Joy Voyles-Brown, Ph.D., R.N., neonatal development specialist
Bess Armstrong, parent and actress

* Infertility
* Antepartum, Neonatal
* Chronic Illness
* Post-NICU
* Clinical/Psychosocial Topics
* Support Group Sessions
* Regional Networking
* Parents' Day

For registration brochure, poster session guidelines, exhibit application or scholarship information, contact: Parent Care, Inc., 9041 Colgate Street, Indianapolis, IN 46268-1210; Phone & FAX (317) 872-9913

Circle #155

Court Backs Private School Choice

The Supreme Court has ruled that parents who place a child with disabilities in a private school because the public school system failed to meet the child's needs, may be eligible for tuition reimbursement under the federal *Individuals with Disabilities Education Act* (IDEA), even if the private school is not approved by the state.

On November 9, 1993, the court issued a unanimous decision in *Florence County School District Four v. Carter*, upholding a lower court's order that the Florence County (South Carolina) school system reimburse the Carter family $35,000 for their daughter's three years at the Trident Academy, a private school for children with learning disabilities that was not approved by the state. At issue in the case was whether or not parents have the right to make a private school placement without school district approval, whether parents making such a placement can seek reimbursement, and whether parents can be reimbursed for a placement in a nonapproved private school.

Shannon Carter's parents placed her at Trident Academy after objecting to the IEP developed by the Florence County school district and requesting a due process hearing. When the due process hearing determined that the school's IEP was inadequate, Shannon's parents filed suit claiming that the school had failed to meet its obligation under the IDEA to provide Shannon with a "free appropriate public education." The parents sought reimbursement for Shannon's tuition and other costs incurred by her placement at Trident. The lower court found that the public school's proposed program was "wholly inadequate" for Shannon, while the private school provided her with "an excellent education in substantial compliance with all the substantive requirements" of IDEA.

The court's opinion, written by Justice Sandra Day O'Connor, affirmed that public schools have the responsibility to provide an appropriate placement or risk paying for whatever alternative placement the parents may find. O'Connor's opinion warned, however, that parents who "change their child's placement...without the consent of the state or local school officials, do so at their own financial risk." They will be entitled to reimbursement only if they can convince a federal judge that the public program violated IDEA *and* that the private program was appropriate under IDEA mandates. O'Connor also cautioned that total reimbursement may not be awarded if the court determines that the cost of the private educational program was "unreasonable." ■

Physician Parents Wanted

The "Physician Access Project" of New England's Information on Disabilities Exchange (INDEX), a University Affiliated Training and Research Program of the national developmental disabilities network, is seeking physicians (especially those in New England) who are parents or relatives of children with disabilities. This project is part of INDEX's efforts to advocate for medical education curriculum reform with regard to treating people with disabilities. Doctors who have an immediate family member with a disability are in a unique position to delineate the changes needed in training and continuing medical education so that appropriate, responsive and knowledgeable community-based health services are more widely accessible to people with developmental disabilities. INDEX plans to include panels of such physicians to present their viewpoints at several national organizations' annual meetings that will be held in Boston during 1994. Any interested physician who is also a parent (or sibling or child) of a person with disabilities can contact Kathleen Damon at NE INDEX,, The Shriver Center, 200 Trapelo Road, Waltham, MA 01254, (617) 642-0248 (V/TDD), (617) 642-0122 (FAX). ■

Students with Disabilities in Regular Classes

The U.S. Department of Education has released a report to Congress showing that as of December 1991, more than 1.6 million students with disabilities—about a third of such children—were being educated in regular classrooms. This represented an increase of almost 100,000 students over the previous year's total.

"Historically, we have had two education systems, one for students with disabilities and one for everybody else," said Judith Heumann, assistant secretary for special education and rehabilitative services. "We are working to create one education system that values all students. The regular classroom in the neighborhood school should be the first option for students with disabilities. Administrators and teachers must receive the training and help they need to make that the best option as well."

The report also contained these findings:

- The two-thirds of students with disabilities who were not served primarily in regular classes were in resource rooms (35%), special classes (25%), special schools (5%), residential facilities (0.8%) or hospitals (0.7%).
- While more than 78 percent of students with speech or language impairments attended regular classes, only seven percent of students with mental retardation were included in regular classes.
- Within three to five years after high school, 20 percent of students with disabilities were functioning independently in living arrangements, social relationships and employment. Another 43 percent were functioning independently in at least two of these categories. Many, however, were working at relatively low-skill, low-paying jobs. ■

Publications

☞ The FAS *Primer* presents an overview of the physical and behavioral characteristics of individuals with Fetal Alcohol Syndrome/Effect. It also recommends strategies for working with children who have FAS/FAE. Contact the Fetal Alcohol Network, 158 Rosemont Ave., Coatesville, PA 19320-3727; $6.00 including postage/handling.

☞ *The Staff* is a newsletter published by Aaron's Associates, 6114 Waterway, Garland, TX 75043, (214) 226-9855. It has articles of interest to children who stutter and their parents. Many articles are written by children themselves. Subscriptions are $15/year (nine issues).

☞ *Hope Through Research: Cerebral Palsy* is a new brochure published by the National Institute of Neurological Disorders and Stroke (NINDS). Free copies can be obtained by contacting NINDS at 9000 Rockville Pike, Bldg 31, Room 8A-16, Bethesda, MD 20892, (800) 352-9424.

☞ A "Toy Resource List" that gives developmental rather than chronological ages for various toys is available from the National Federation of the Blind. An addendum will be available in August 1994. The list is free. Contact: NFB POBC, Committee on the Blind Multi-Handicapped Child, 1912 Tracy Road, Northwood, OH 43619, (419) 666-6212.

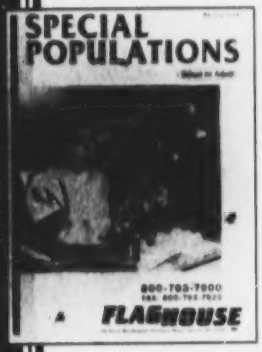
☞ *Understanding Klinefelter Syndrome: A guide for XXY Males and Their Families* describes currently available treatments and early childhood development, and offers advice for parents on deciding whom to tell—and how much to tell—about their son's extra chromosome. Related sections offer tips for detecting language problems early, helpful hints for teachers and advice for parents seeking special educational services. The booklet also deals with adolescence, testosterone treatment, sexuality, infertility and health considerations that are unique to XXY males. The booklet is available free from The National Institute of Child Health and Human Development, P.O. Box 29111, Washington, DC 20040, (301) 496-5133.

☞ New publications from the PACER Center (4826 Chicago Ave. South, Minneapolis, MN 55417, 612-827-2966) include: *Begin the Between: Planning for the Transition from High School to Adult Life* ($5.00), *Supported Employment: A Step-by-Step Guide* ($8.00) *and Speak Up For Health* ($10.00), a guide for parents of adolescents with chronic illnesses and disabilities as they prepare their children to make independent health care decisions. *Our Children, Our Hopes* ($35.00 purchase or $10.00/three-week rental) is a 15-minute, closed-captioned videotape in which African American parents of children with disabilities discuss their unique experiences. All prices include postage/handling.

☞ The Human Growth Foundation (7777 Leesburg Pike, Falls Church, VA 22043, 800-451-6434) offers the following free publications: *Patterns of Growth, Growth Hormone Deficiency, Turner Syndrome, Intrauterine Growth Retardation, Achondroplasia, Short & OK: A Guide for Parents of Short Children, Short Stuff* (written and illustrated by a nine-year-old boy with growth hormone deficiency about his experience with growth hormone therapy).

FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE



Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- Aquatic Aids/Sports Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE

150 No. MacQuesten Pkwy., Suite 95307 Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922
Circle #29

The Helmet

continued from page 39

could tell that he was trying to figure out why a three-year-old was wearing a helmet. As he strapped Mike's car seat into the shiny new car for a test drive, his curiosity won out and he asked, "Why is he wearing that helmet?"

"It's for protection," I replied, slipping behind the wheel of the new car. "It's because I'm such a bad driver. Would you care to join us for our test spin?"

I love my son, and I am glad that I came along for this bumpy ride of being his mother. Despite the peculiar looks we get, I know Mike is more likely to be physically injured without the helmet's protection than psychologically injured by wearing it. Mike's had more than his share of trips to the emergency room, but the helmet has saved him many other trips. Perhaps I've benefited as well—dealing with situations involving Mike's helmet has taught me a lot about how to handle people, and I've learned not to worry so much about other people's perceptions and reactions. ■

Joni Pelta is an at-home mother, room parent and active volunteer in her children's schools. She and her husband, Murray, reside in suburban Atlanta and have two children—Mark, age six and Michael, age four. Before becoming a "domestic goddess," Joni earned an MBA from the University of Southern California, was editor and senior market analyst at a newsletter in California and worked as a market researcher in Chicago.

Friends & Classmates

Children in Beckley, West Virginia participated in a number of activities during last October's "National Disability Awareness Month." Adults with disabilities visited every class at Cranberry-Prosperity Elementary School and answered children's questions. Older students read books about people with disabilities and parents of younger students borrowed books to read with their children. In physical education classes, teacher Susan Davis offered children the opportunity to "experience" briefly what it is like to have a disability by donning waxed paper glasses, wearing ear protectors or trying out adaptive equipment like wheelchairs, walkers, crutches and communication boards. Students were also encouraged to put their thoughts in writing.

These essays were written by Amanda Sears, Andrea Black and Dane Toney, students in Debby Aliff's second grade classroom. Amanda has spina bifida.

Amanda Sears, Dane Toney and Andrea Black are classmates at Cranberry-Prosperity Elementary School in Beckley, West Virginia.

I know someone special to me. She is a very special person to everyone. She is like us in every way. She is someone I really like. This person is Amanda Sears!

—Andrea Black

It's hard getting up the steps. I know I have a disability. When I go to the store, the other kids stare at me. Mom says to stare back, but I don't. I try walking, but I fall down. Sometimes I can walk 20 steps. The doctor said that I will walk by myself maybe.

—Amanda Sears

Amanda has a disability. She has crutches. She cannot walk without them. She gets around well. She can do almost everything I do. She likes to do lots of things. She is very nice. She works very hard.

—Dane Toney

Eight-month-old Jacob Wilkins

Familiar Faces

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 309, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone else in the photo. If you like, you can also write a few sentences about your child/family. Then look for a familiar face in an upcoming issue!

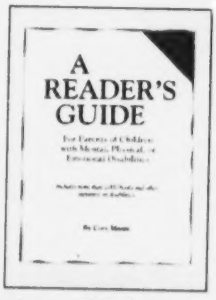
EXCEPTIONAL PARENT LIBRARY

DISABILITY, GENERAL

ADAPTIVE PLAY FOR SPECIAL NEEDS CHILDREN STRATEGIES TO ENHANCE COMMUNICATIONS AND LEARNING
by Caroline Ramsey Musselwhite
(PE042OD) $27.00

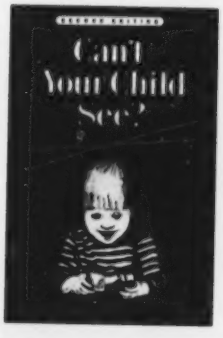
Adaptive play refers to play that has been altered in form, complexity, or intent to serve the needs of children with disabilities. This book summarizes recent advances in using play as a learning tool, developing adaptive play materials, teaching specific skills through play, and supporting the use of play in all settings.

A READER'S GUIDE FOR PARENTS OF CHILDREN WITH MENTAL, PHYSICAL, OR EMOTIONAL DISABILITIES
Third Edition
by Cory Moore
(WB032OD) 248 pp.
$14.95



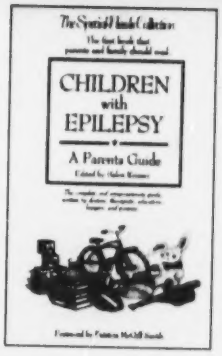
A READER'S GUIDE is an indispensable tool for parents, teachers, and librarians — virtually anyone who needs to find the most current, authoritative information in print about children with disabilities. This useful annotated bibliography lists more than one thousand books and other resources on disabilities. Each listing has been carefully selected for parents.

CAN'T YOUR CHILD SEE? A GUIDE FOR PARENTS OF VISUALLY IMPAIRED CHILDREN
(Second Edition)
by Eileen P. Scott, James E. Jan, and Roger D. Freeman
(PE041OD) $23.00



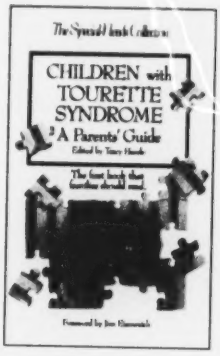
This second edition offers parents optimistic, practical guidelines for helping visually impaired children reach their full potential. The crucial role of parents is stressed, as is the need for their involvement and for support services. In easy-to-read language, the book examines the impact severe visual impairment can have on normal child development and offers realistic suggestions for managing related problems.

CHILDREN WITH EPILEPSY: A PARENTS' GUIDE
Edited by Helen Reisner
(WB018OD) 314 pp.
$14.95/



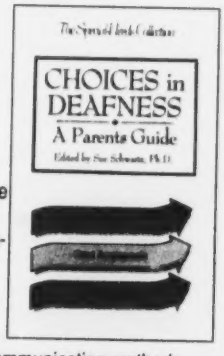
CHILDREN WITH EPILEPSY offers valuable direction and support to parents of a child with epilepsy. With chapters on diagnosis, medications, daily care, family life, advocacy, and special education, this book provides an in-depth look at epilepsy, and its various treatments, as well as its impact on the child and family.

CHILDREN WITH TOURETTE SYNDROME: A PARENTS' GUIDE
Edited by Tracy Haerle
(WB016OD) 340 pp.
$14.95



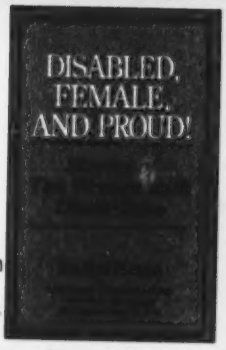
This parents' guide to Tourette Syndrome explains the disorder, including its symptoms, causes, and medications, as well as the disorders which are commonly linked with it. Other chapters cover family life, education, advocacy, and legal rights. Parent Statements appear throughout, offering insight, advice, and encouragement for the reader.

CHOICES IN DEAFNESS: A PARENTS' GUIDE
by Sue Schwartz, Ph.D.
(WB025OD) 212 pp.
$14.95



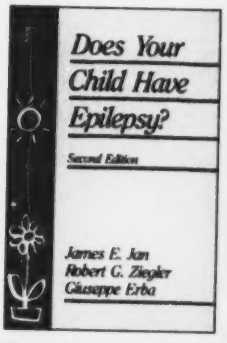
Parents of children with hearing impairments face a difficult decision — which method of communication is the most appropriate for their child? With its clear, objective descriptions of the three predominant communication methods, CHOICES IN DEAFNESS provides valuable guidance in sorting out the options.

DISABLED, FEMALE AND PROUD! STORIES OF TEN WOMEN WITH DISABILITIES
by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance
(GW003EP) $12.95
(Limited Supply)



Offers young women with disabilities empowering role models and the powerful message that they have full lives ahead of them. Offers parents and educators a unique way to help young people learn that making choices — about school, work, family, love — is what being disabled, female and proud is all about.

DOES YOUR CHILD HAVE EPILEPSY? (SECOND EDITION)
by James E. Jan, Robert G. Ziegler and Giuseppe Erba
(PE036OD) $22.00



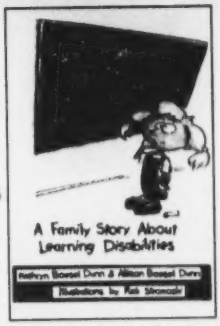
Written by three well-known pediatric specialists, this book provides information on the most common type of seizures, causes, principles of treatment, investigations and outcome, with a wide range of helpful suggestions from infancy to early adulthood. This book is highly recommended for parents and grandparents of children with epilepsy, older children with seizures and their siblings, teachers, health professionals, and other caregivers.

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
by Monte Mace
(TP026OD) $12.95

The Illustrated Directory empowers parents and persons with disabilities by widening choices about products. There are many products available — if you know where to find them. Sadly, many retail outlets do not carry a wide choice of products. This Directory shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

To order, use the order form on page 64, or call 1-800-535-1910

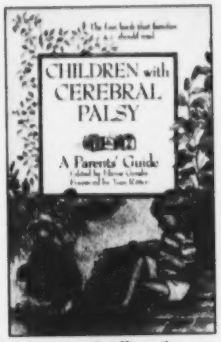
TROUBLE WITH SCHOOL
A FAMILY STORY ABOUT LEARNING DISABILITIES
by Allison & Kathryn Dunn
(WB028LD) 32 pp. $9.95



TROUBLE WITH SCHOOL is an autobiographical tale about how one family handled the challenge of diagnosing and meeting the needs of a child with a learning disability (LD). The book's unique dual narrative allows the child and parent to take turns telling their side of the story. It takes a clear look at the warning signs and common problems associated with LD.

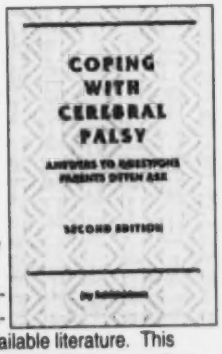
DISABILITY, PHYSICAL

CHILDREN WITH CEREBRAL PALSY
A PARENTS' GUIDE
Edited by Elaine Geralis
(WB012PD) 434 pp. $14.95



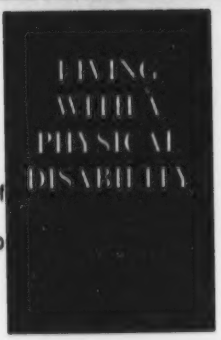
CHILDREN WITH CEREBRAL PALSY is essential reading for all parents who need to learn about CP and how it will affect their child and family. Written by doctors, therapists, educators, and parents, this fine book offers the perfect balance of information and support, presented in an easy-to-understand, compassionate style. It is an invaluable resource for families with a child with CP.

COPING WITH CEREBRAL PALSY
ANSWERS TO QUESTIONS PARENTS OFTEN ASK
(Second Edition)
by Jay Schliechkorn
(PE037PD) $24.00



Parents of children and adults with cerebral palsy often have many questions that are not satisfactorily answered by professionals or through the available literature. This book provides parents with answers to more than 300 questions that have been carefully researched and represents the author's 40 years of experience with parents of individuals with cerebral palsy. Appendixes include a glossary of terms, a listing of 60 special videotapes, and recommended readings.

LIVING WITH A PHYSICAL DISABILITY
by Jill Krementz
(SS014PD) $18.00



Portrays the indomitable spirit of children who live with disabilities. This book is an inspiring gift of hope from 12 children ranging in age from six to 16 whose physical disabilities include blindness, dwarfism, paralysis, birth anomalies, spasticity and CP. Captured in text and photos, these children tell their own stories and speak with candor about their lives.

TEACHING THE YOUNG CHILD WITH MOTOR DELAYS:
A GUIDE FOR PARENTS AND PROFESSIONALS
by Marci J. Hanson and Susan R. Harris
(PE049PD) $27.00

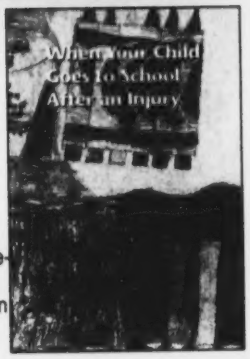
This easy-to-read guide bridges the gap between parents and professionals who work with movement-impaired children between the ages of birth and three years. The 228-page book has two purposes; to provide information to parents on how motor development influences other areas of child development and to provide teaching strategies and therapy activities for use in the home.

THE WHEELCHAIR TRAVELER*
by Douglass R. Annand
(WT015PD) $20.00

A practical dictionary of information for the traveler with a disability. Includes accessibility ratings of hotels/motels in the U.S., Canada and Mexico and useful tips for comfortable travel. Although written for adults, it provides helpful information for parents traveling with a child with a disability.

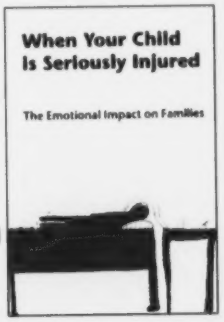
INJURY

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY.
by Marilyn Lash
(EP006ML) $7.50 (includes s&h)



To guide parents through one of the most anguishing experiences a family can undergo, rehabilitation specialists at Tufts University School of Medicine and the New England Medical Center have produced a guide of practical, clear-eyed advice, written with input from parents with first-hand knowledge of the subject. Seventy-two pages long, *When Your Child Goes to School After an Injury* speaks in frank terms about the issues parents need to confront about their child's future schooling, health care and social needs.

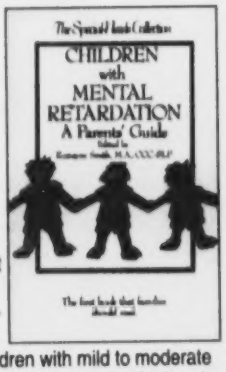
WHEN YOUR CHILD IS SERIOUSLY INJURED: THE EMOTIONAL IMPACT ON FAMILIES
by Marilyn Lash
(EP005ML) $4.50 (includes s&h)



A 40-page practical guide discusses the hospitalization of injured children from arrival at the emergency room through discharge planning for rehabilitation and home. Topics include preparing for hospital visits, reaction to loss, helping siblings, and practical suggestions for coping. Developed by a Family Task Force, it includes a Parents' Bill of Rights, resource listings and suggested readings.

MENTAL RETARDATION

CHILDREN WITH MENTAL RETARDATION
A PARENTS' GUIDE
Edited by Romayne Smith, M.A, CCC-SLP
(WB007MR) 437 pp. $14.95

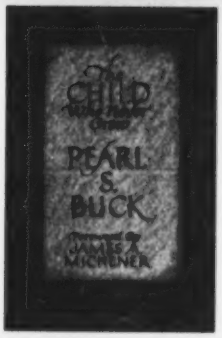


This book is a complete guide to everything parents need to know about raising their child and meeting her varied medical, therapeutic, and educational needs. Children with mild to moderate mental retardation, whether diagnosed at birth or in early childhood, require more help than usual in all areas of development, and their parents need to be well informed and involved every step of the way.

To order, use the order form on page 64, or call *1-800-535-1910*

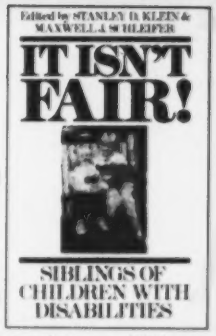
EXCEPTIONAL PARENT LIBRARY

DIFFERENCES IN COMMON STRAIGHT TALK ON MENTAL RETARDATION, DOWN SYNDROME, AND LIFE
by Marilyn Trainer
(WB009MR) 236 pp.
$14.95
In this engaging collection of essays, Marilyn Trainer draws on her experience as the mother of a child with Down syndrome, now in his twenties. With candor and humor, she brings a fresh, candid outlook to the challenges, hopes, and fears of family life — a life shaped by a child with Down syndrome, but one which strikes a common chord in all of us.

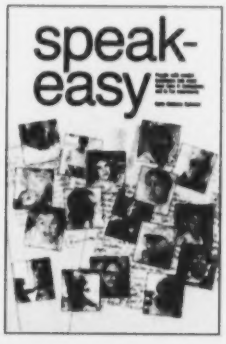


THE CHILD WHO NEVER GREW
by Pearl S. Buck
Foreword by James A. Michener
(WB008MR) 107 pp.
$14.95
The Woodbine House edition of THE CHILD WHO NEVER GREW brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation. New material written especially for this edition, amplifies her story and gives the book an important historical perspective. This landmark book urges society forward toward greater awareness of people with mental retardation.

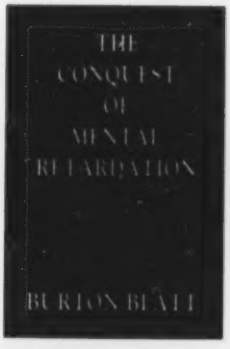
GENERAL



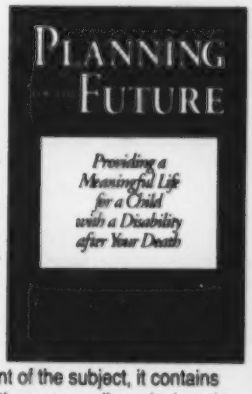
IT ISN'T FAIR! SIBLINGS OF CHILDREN WITH DISABILITIES
Edited by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.
(EP001EP) $14.95
Includes all the material published in *Exceptional Parent* since 1971 on the topic of relationships between sisters and brothers when one child has a disability. Features chapters by parents, siblings and professionals.



SPEAKEASY PEOPLE WITH MENTAL HANDICAPS TALK ABOUT THEIR LIVES IN INSTITUTIONS AND IN THE COMMUNITY
by Karin Melberg Schwier
(PE044MR) $16.00
In this unique and compelling collection, people labeled mentally handicapped speak honestly and powerfully about their lives in large institutions and in the community. Through intimate interviews, the author has captured the dreams, fears, frustrations, and humor of people who were exiled for being different but battled social barriers to establish independence. Emerging from these pages are colorful, resilient, and thoughtful individuals.



THE CONQUEST OF MENTAL RETARDATION
by Burton Blatt
(PE047MR) $38.00
(Hardcover)
The author lays out the basics of the field — history, classification, and definitions — but he also discusses controversies; nature versus nurture, deinstitutionalization versus institutionalization, and the educability hypothesis. Moreover, each of these topics is placed within a broader context — social, political, and moral. A single, powerfully felt conviction infuses the whole: One's value as a human being does not have to be deserved.



PLANNING FOR THE FUTURE
by Mark Russell
(AP024OD) $24.95
A comprehensive guide for parents of children with disabilities. The 400 pg. softcover publication provides all the info. parents must consider as they plan for their child's life after their own deaths. A comprehensive, authoritative treatment of the subject, it contains twelve chapters and three appendices designed to give all the information parents need to ensure a happy and meaningful life for their children after they die. It draws on the authors' extensive personal experience in planning for families with children who have disabilities.
L. Mark Russell, a co-author, is an attorney and is one of the nation's leading authorities on life and estate planning for families who have a child with a disability. Mr. Russell's earlier book, *Alternatives*, published in 1983, has been considered a definitive resource on this subject.

EXCEPTIONAL PARENT LIBRARY

Mail to: Dept. EP9402, P.O. Box 8045, Brick, N.J. 08723 **or call (800) 535-1910**

Name
Address
City State Zip
Telephone

I have enclosed my check payable to Exceptional Parent or charge to my:
❑ Visa
❑ Mastercard ☐☐☐☐-☐☐☐☐-☐☐☐☐-☐☐☐☐
Exp. Date Signature

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES
U.S. – $3.50 for 1 item:
75¢ for each additional item.
Foreign – $6.50 for 1 item:
75¢ for each additional item.

Sub-Total
NJ Residents 6% Sales Tax
Shipping
TOTAL

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas

F'93

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.

AND THEN BACK OUT AGAIN."

At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

P-CAP

CHRYSLER CORPORATION

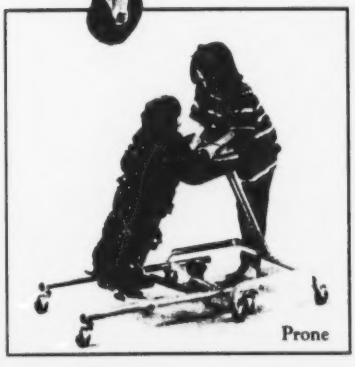
For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Circle #90

Tumble Forms®
tristander™

Industrial Design Excellence Award
SILVER 1993

Vertical


Prone

Supine

Triple Your Therapy Options

The new TriStander™ from Tumble Forms® does the job of three standers. Its unique design allows vertical, prone, or supine standing, so you can count on a single stander to meet a variety of positioning needs. The height-adjustable positioning modules accommodate children from **32 to 45** inches tall, so you can use it with a number of pediatric clients, or let it "grow" with a single patient. And because one stander does it all, you save valuable floor space, as well as money!

Preston.
A BISSELL HEALTHCARE COMPANY

For more information call:
1-800-631-7277

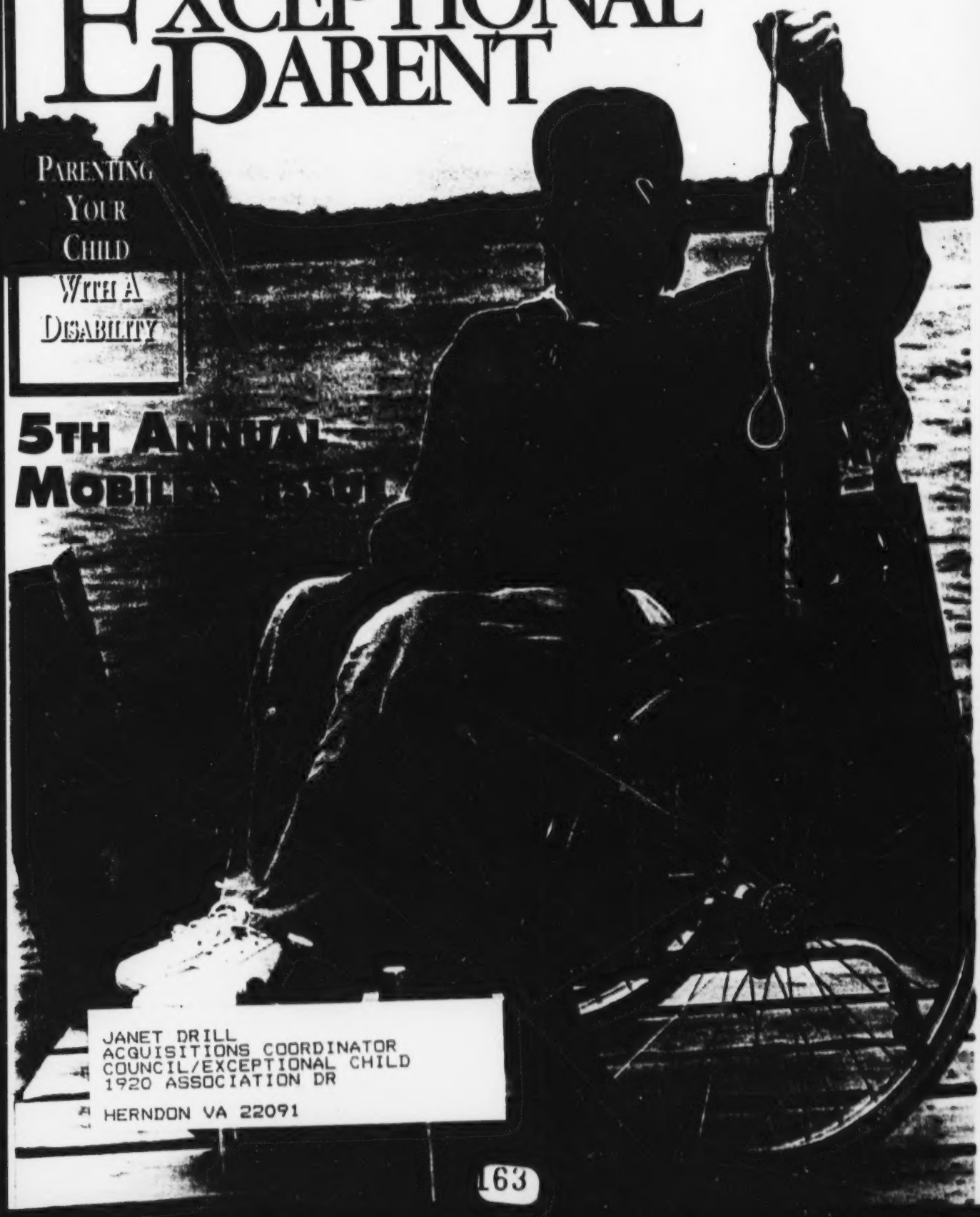
P.O. Box 89, Dept. 1369, Jackson, MI 49204-0089

1993 BISSELL Healthcare Corporation

MARCH 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY



5TH ANNUAL
MOBI

JANET DRILL
ACQUISITIONS COORDINATOR
COUNCIL/EXCEPTIONAL CHILD
1920 ASSOCIATION DR

HERNDON VA 22091

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.

[2] Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford Ford and Lincoln-Mercury Divisions

Circle #30

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

March 1994 Volume 24 Issue 3

FIFTH ANNUAL MOBILITY ISSUE

18 Doing What Works Best *by Kathy Olsen*
"Choosing to use a wheelchair is not a failure."

23 Wheeled Mobility Selection: A Guide For Parents
A detailed look at wheelchair options.

33 Powered Mobility For Your Child? *by Linda Petty*
When is a child ready for a powered wheelchair?

37 Directory of Wheelchair Manufacturers

41 Directory of Cushion Manufacturers

Page 18

Page 59

COVER: 14-year-old Matt Gudel proudly displays the Catch of the Day. Matt attends the annual fishing events sponsored by Fishing Has No Boundaries of Hayward, WS. Fishing Has No Boundaries is a volunteer-staffed organization dedicated to opening up the great outdoors to people with disabilities, through fishing events held annually in a number of states. For more information, see story in What's Happening, page 80 (cover photo courtesy of Windmill Photography).

FEATURES

45 Lost In the Mall! *by Linda Kratz*
"How in the world can you lose a child in a wheelchair?"

47 In Defense of My Daughter *by Judy Horton*
Teaching children not to tease

55 Selecting A Summer Camp
Suggestions for parents

56 The ABLEDATA Database of Assistive Technology *by Alynne Landers*
19,000 products for children and adults with disabilities

DEPARTMENTS

2 Editor's Desk
4 Letters to the Editor
7 Family Support
53 Children's Health Notes
59 Fathers' Voices
62 Role Models
64 Directory of Advertisers
67 Research
69 Point of View
78 Childrens' Page
80 What's Happening

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005.

All rights reserved, Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation.

POSTMASTER: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only); All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries*: No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

EDITOR'S DESK

Stanley D. Klein Ph.D.

Welcome to our fifth annual mobility guide. Each year, in articles like "Wheeled Mobility Selection: A Guide for Parents," "Doing What Works Best," and "Powered Mobility for Your Child," we provide information about wheeled mobility and the range of choices available to meet the individual needs of children and teenagers. Special thanks to our friends at ABLEDATA who provided information for the article on wheeled mobility selection and the product directories. In addition to being a database of thousands of products, ABLEDATA offers many services which are described in "The ABLEDATA Database of Assistive Technology."

Parenting is what Exceptional Parent is all about—about Paul J. Karch and his daughter ("Rachel, Say 'Hi'"), about the Kratz family's memorable trip to the mall ("Lost in the Mall!"), and about Judy Horton teaching someone else's child about her own ("In Defense of My Daughter"). Each of these articles shares the adventures of everyday family and community life from the most important experts—parents.

In "Our Civil War Over Residential Care," Richard Haddad describes how some parents and professionals have "allowed ideology to bury their compassion," with the result that parents do not find the help they need to make very complicated decisions on behalf of their children. This article should inspire all of us to respect each other's choices and appreciate that we share a common goal—the creation of opportunities and options for children and adults with disabilities, and their parents.

Readers were delighted to get to know Judy Heumann, Assistant Secretary of Education, Office of Special Education & Rehabilitative Services (OSERS), via our interview with her (February 1994). In Part Two, she shares her perspective on policy priorities and other challenges.

In this issue, we also are pleased to feature material on health care from Peggy Mann Rinehart—parent, journalist, and member of our *Exceptional Parent* Editorial Advisory Board. Our readers also discuss the critical issue of health care reform in Letters to the Editor. As in the past, we urge everyone to actively advocate for the kinds of changes needed to insure decent health care for children with disabilities and special health care needs—and for all other citizens as well. With this issue, we welcome another new member to the Editorial Advisory Board—Dina Loebl of New York University.

Meetings

In January, Joe Valenzano, Terri Sutera and I met in Washington with many dedicated parents and professionals involved in early intervention programs and other efforts to serve children and families. It was exciting to interact with so many devoted people, to learn about services for families and to get feedback about the magazine. In this issue, on the Children's Page, we are following one suggestion we received—that we continue to include materials from siblings as well as children with disabilities. As spring arrives, we look forward to meeting many more readers at meetings throughout the country.

Children's Art and Reader Photos

Exceptional Parent is now using children's artwork to illustrate feature articles and departments. We invite your children to share their work with our readers. Put the picture's title along with the child's name and address on the back of submitted artwork.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers? On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone else in the photo. You can also write a few sentences about your child/family.

Send artwork and photos to: *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146.

Weather or Not

Earthquakes, snowstorms and other disruptive "natural events" resulted in the February issue being received late by many readers. Unfortunately, the production of this issue was similarly delayed.

EXCEPTIONAL PARENT

Editor in Chief
Stanley D. Klein, Ph.D.
Professor of Psychology,
New England
College of Optometry

Assistant Editor
Kim Schive

Editorial Staff
Andrew M. Bissaro
Valerie Steele

Editorial Interns
Simone Albeck
Zlati Meyer
Annabel Tan

Consulting Editor
Maxwell J. Schleifer, Ph.D.

Editorial Office
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

President and Publisher
Joseph M. Valenzano, Jr.

Vice President, Marketing
Terri M. Sutera

Vice President, Sales
Kerry J. Cannon

Circulation Manager
Kimberly Tuzik

Director, Organizational Relationships
R.K. Hopkins, Jr.

Vice President, Manufacturing & Distribution
Lawrence Qualiano

Finance Manager
Roy Whitaker

Publishing Office
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240

Art Director
Charles A. Horn

Assistant Art Directors
Donna R. Hunter
Frank N. Avellino

Creative and Production
Morris/Weber & Associates, Inc.
Clifton, NJ 07011

Color Separation/Film Preparation
Plate Masters Inc.
Carlstadt, NJ 07072

Exceptional Parent magazine
was founded in 1971 by
Stanley D. Klein, Ph.D. and
Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 65

BPA International Consumer Magazine Membership Applied for August 1993

During a 3 year period, children grow an average of 2" in femur length, 1.5" in hip width, and 2.5" in back height.

— extrapolated from *Human Dimensions and Interior Space*

The revolutionary Jay® GS Growth and Positioning System is designed to grow that much and more.

The system includes a new growth Cushion, a new growth Back, and the Jay® Adjustable Solid Seat. Together, these components help position the child's hips and back properly at every step of the growth process. The system is also designed to reduce spasticity and tone.

Call for a free demonstration so that you too can see what a difference a Jay makes!

▲ The Jay GS Growth & Positioning System

JAY. MEDICAL

Jay Medical, Ltd.
P.O. Box 18656
Boulder, Colorado
80308-8656 USA
(303) 442-5529

Toll-free
(800) 648-8282

In Canada, call
(800) 263-3390

© 1992, Jay Medical, Ltd

Letters to the Editor

A Lifeline

Enclosed are many years of *Exceptional Parent* magazines. We have saved them all. Now, perhaps you can pass them on to someone else who can use them. *Exceptional Parent* was truly a lifeline for us, especially in the first few years of Karl's life. Trying to find out what was wrong and how we could fix it seemed to consume us.

Today, Karl is 24 years old and lives in a group home quite near us. He is a wonderful young man and has touched the lives of so many people. He has been an altar boy at our parish for 11 years! He is well known and loved by many people.

In December 1991, we noticed a small lump on the back of his neck. To make a long story short, Karl was diagnosed with lymphoma and had six rounds of chemotherapy. He was very sick with the chemotherapy. As always, he was cheerful and accepted what had to be done. We have learned a lot from our son!

Karl and his girlfriend, Gail, who lives in another group home in the community.

A.J., Illinois

Search Letter Helps

I am a big admirer of your magazine. I never thought in a million years that you would run my Search letter, but I am so glad you did. Last month, I made contact with another woman who had a son with Asperger's syndrome. She was the first parent I have ever talked to who really understood. If she started a sentence, I finished it, and vice versa. I cannot tell you what strength and power that gave me. Once again, many thanks!

L.N., Oregon

Health Care Concerns

My daughter has cerebral palsy and epilepsy. She cannot do anything for herself. She is a very happy, smiling child that knows no one as a stranger.

I am a low income person who does not abuse the system in any way. My daughter receives SSI and Medicaid. I have a number of concerns about health care reform.

One concern has to do with durable medical equipment. In order for my daughter to be transported to school, she has to have a wheelchair. Medicaid will buy one new wheelchair every five years. In between new chairs, Medicaid pays for repairs. My daughter received her first wheelchair in 1989. Before school started last fall, her chair needed to be reconstructed to fit her, and other parts of the chair needed adjustment and replacement. The cost of the new chair in 1989 was $2,500. In 1993, the reconstruction and other adjustments cost $3,500. Why didn't Medicaid just buy a new chair and save the $3,500 they put into a worn out chair? My daughter becomes eligible to receive a new chair six months after these expensive repairs on the old one.

The government accuses people of abusing the system. The way I see it is that their own rules cause abuse!

P.D., Indiana

■ Thank you for the article on the government's proposed health care plan and how it applies to individuals with disabilities. I agree that it is time to stop denying health care coverage to individuals because they have disabilities, but there are many other questions we must ask.

The current health care proposal from our President would stop "unnecessary treatment." Does that mean that if you have a physical disability, you won't be able to get surgeries or therapy just because these interventions won't "cure" your condition? Will some be more equal than others when it comes to providing health care to people with disabilities?

As the parent of a son with a disability, I was very excited about the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). It seemed like so many opportunities were opening for him. The IDEA and the ADA recognize the fact that all members of our society are important and precious, but I am suspicious of the President's health care plan. I want to know the truth now before a doctor tells me that my son can't have treatment because it won't "fix" his disability.

Please join me in writing to your legislators. And don't forget to drop a line to the Clintons as well.

S.M., Missouri

■ I have eagerly been reading every scrap of information I can get my hands on concerning health care reform, including the articles in *Exceptional Parent*. The more I uncover about the President's plan, however, the more alarmed I become.

As the mother of three children, two of whom have disabilities, there are a number of things that I'm concerned about in the President's plan. I'm worried that there will be fewer specialists, and longer waits for an appointment when one is needed. I'm concerned that health care will be rationed, creating long waiting lists for hospital surgeries and sophisticated diagnostic tests. My daughter, who suddenly developed cataracts, would have lost her vision completely if she had been forced to wait that long to have them removed. Instead, she was in surgery less than two weeks after we first discovered her condition and is now making progress with her visual skills.

To be fair, there are some good things about the plan as well—things like prohibiting insurers from denying coverage or charging exorbitant premiums to those who have pre-existing conditions and making health coverage more available to low-income people. I just don't think the President is going about it in the right way.

There are a number of other plans being proposed. You would be doing the readers of this publication a tremendous service by informing them about *all* of the proposals.

D.E.C., Massachusetts

We welcome all letters from readers—reactions to articles, suggestions, opinions, complaints. Write or fax:

Letters to the Editor
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005.
Fax: (617) 730-8742

Merrill Lynch makes a difference.
We are the only full-service firm to provide specialized services for the deaf and hard-of-hearing.

The Difference Is Merrill Lynch.

Merrill Lynch will help you meet your financial goals through our many available services:

- ❑ Over 80 Merrill Lynch Financial Consultants equipped with TTYs and voice amplifiers to provide access to our many financial products and services.
- ❑ Product videotapes with captions.
- ❑ National toll-free lines through TTY and voice amplification for account inquiries, information, suggestions, and free publications.
- ❑ Educational seminar program dedicated to the deaf and hard-of-hearing population.

To discuss investment strategies, please call Merrill Lynch. We will put you in touch with a Merrill Lynch Financial Consultant who can design an investment plan that best suits your needs.

The difference is Merrill Lynch.

Call 1-800-765-4833 TTY ext. 6489
1-800-765-4464 Voice Amplification
1-800-637-7455 Voice ext. 6489

To receive a free copy of our brochure, mail to:
Merrill Lynch Response Center
P.O. Box 30200, New Brunswick, NJ 08989-0200

Name _____ Address _____

City _____ State_____ Zip _____

Business Phone (___) _____

Merrill Lynch clients, please give name and office address of your Financial Consultant: _____

6489

Merrill Lynch
A tradition of trust.

©1994 Merrill Lynch, Pierce, Fenner & Smith Inc. Member SIPC

Circle #168

Parents Search

Jacobsen's Syndrome

We have a 28-month-old daughter who has been diagnosed with an eleventh chromosome deletion at q 24.1, also called Jacobsen's Syndrome. Symptoms include a triangularly-shaped head, high palate, congenital heart defects, developmental delays and physical growth retardation. Our daughter is doing very well in many areas, but is delayed in gross motor and speech skills. I am interested in talking with parents who have a similarly diagnosed child.

E.H.
Indiana

Chromosome Translocation

My five-and-a-half-year-old son has been diagnosed recently with a complex translocation between chromosomes five and six with some segments flipping upside down. It is not known if genetic material was lost. He has had one positive and two negative Fragile X tests. He has a normal EEG and MRI, but has a seizure disorder. He also has mild mental retardation, swallowing difficulties, global developmental delays, speech difficulties, a heart murmur and autistic tendencies.

Doctors, genetic counselors and NORD have been unable to tell me anything about my son's chromosomal abnormality. They all tell me that there isn't another documented case like his. I'd welcome information or referrals from anyone who can help.

K.H.
Washington

Congenital Cytomegalovirus

Our two-year-old son has congenital cytomegalovirus (CMV). Chase was given the "orphan drug" Ganciclovir or DHPG (dihydroxy propoxymethl guanine) for six weeks after birth as part of the Ganciclovir study at Arkansas Children's Hospital.

Chase has intracerebral calcifications and profound left sensorineural hearing loss, and is developmentally delayed. He is in an early intervention program and receives occupational, speech and physical therapy. We are eager to correspond with other families who have a child with congenital CMV.

P.G. & B.G.
Arkansas

Macroglossia

As the parent of a beautiful premature girl born at 28 weeks gestation, I am interested in finding parents of other children with a condition known as macroglossia, or enlarged tongue. Sarah is currently undergoing genetic testing to find out if she has any other birth defects or any of the many syndromes that are sometimes associated with this condition. I would like to hear from parents who have had children with macroglossia to find out about the treatments their children receive and exchange experiences.

C.K.H.
Ohio

48XXXX Syndrome

Our four-year-old daughter has 48XXXX syndrome. Her pathologist told us that there are only about thirty known cases of this very rare syndrome. Our daughter has a severe speech impediment. Her muscle tone is low, and she wears Phillips splint braces. Her cognitive development and fine motor skills are age appropriate. We would like to know if there are others with this syndrome.

N.T.
Indiana

Parents with Learning Disabilities

My husband and I have a dilemma and don't know who to ask for help. We both have learning disabilities. My husband is severely dyslexic and I am mildly dyslexic and dysgraphic. We both have been tested and received some assistance in overcoming our difficulties. We are now concerned about our two-year-old daughter. Considering our track record, chances are good that she will also have some form of learning disability. We had considered placing her in a local parochial school when she is old enough to start kindergarten. Unfortunately they do not have the capabilities to handle children with learning disabilties.

Editorial Advisory Board

- LARRY BELFORD, Director, Marketing Research & Strategic Analysis, Ciba-Geigy Pharmaceuticals, Summit, NJ
- LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
- T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
- FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
- ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
- ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
- MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
- SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
- BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
- SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
- STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
- HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
- DAVID HERSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
- GOODWIN D. KATZEFF, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
- SUSAN M. KLEIN, Ph.D., Professor of Special Education, Department of Education, Indiana University, Bloomington, IN
- DINA LOEB, Ed.D., OTR., Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
- EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
- JAMES MAY, M.A., M.Ed., Project Director of the National Fathers' Network, Bellevue, WA
- JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
- EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
- BETTY PEKELDER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
- STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
- HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
- SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
- PEGGY MANN RIEHART, B.A., Parent and Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
- JEROME ROBBER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
- MARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
- BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
- HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
- CAROL TEGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
- HAROLD TUREK, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
- IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

MIC-KEY®

Skin Level Gastrostomy Feeding Kit

Additional Sizes Immediately Available !

Features . . .

- Designed for improved cosmetic image
- Designed for easy placement and exchange
- Complete size range for Adults and Pediatric patients
- No obturator needed
- Available with:
  - Patented SECUR-LOCK® Extension Set
    - that virtually eliminates disconnects
    - with separate feeding and medication ports
  - Bolus feeding set for easy bolus feeding
- Superior balloon design
  - SHUR-FORM® balloon system assures proper inflation.
- Stoma measuring device
  - Easy to read
  - Provides consistent, accurate measurements.
- Made of clear medical grade silicone material

MEDICAL INNOVATIONS CORPORATION
A DIVISION OF BALLARD MEDICAL PRODUCTS

Ballard Medical Products
12050 South Lone Peak Parkway, Draper, Utah
(801) 572-6800 • Fax: (801) 572-6999

For More Information Call: 1-(800)-629-5591

U.S. Patent Nos. 4,798,592 • 4,685,901 • 4,701,163
Other U.S. patents pending and foreign patents issued and pending

We need to know at what age she will be old enough to be tested and where the testing can be done. I was 16 and my husband was 30 before our learning disabilities were properly diagnosed. If my daughter has inherited our learning disabilities, I have no intention of letting her go through the emotional scarring we went through.

L.J.J.
Maryland

Cart for Ventilator

I have a two-and-a-half-year-old, active son who is on a ventilator. He rolls, sits, and is starting to crawl. His therapists believe he will walk. I would like suggestions for a compact, lightweight cart to hold his ventilator and oxygen that would allow him to be independently mobile.

D.G.
Indiana

Catheterization Help

My granddaughter was born with spina bifida and hydrocephalus. As a result, she has no bladder control. To empty her bladder, she must be catheterized every four hours. At present, a small feeding tube is being used as a catheterizing device. She is reaching the age of adolescence and wants to learn to catheterize herself, however, it is very difficult for her to insert the catheter in the appropriate place while sitting on the toilet. The visiting nurse tried to teach her one catheterization technique, but it did not work.

Are there readers of your magazine who have had a girl that needed to learn this procedure? We would appreciate hearing from any family that would be willing to share a method that worked for their child.

B.F.S.
Vermont

Inclusive School Districts in New England

We have a six-year-old daughter with special needs who presently attends a kindergarten with full inclusion. We are very pleased with her progress in the program and would like to continue a similar program. We are trying to relocate to New England and seek assistance in finding school districts with full inclusion.

J.H.
Ohio

Generalized Dystonia

My sixteen-year-old daughter, Angela, was diagnosed with torsion dystonia at age fifteen. Torsion dystonia is a neurological disorder characterized by involuntary, sustained muscle contractions. This causes twisting, repetitive movements and abnormal postures. Angela's dystonia has progressed throughout her body and causes a lot of pain in her hips. She has spasms, jerks and tremors which accompany the dystonic movements, and is now in a wheelchair.

Adjusting to dystonia has been very difficult for everyone in our family—but especially for Angela. Since generalized dystonia is relatively rare, she knows no other teenagers with this condition. She is having a difficult time emotionally. Are there any other families reading this who have had to learn to cope with a non-curable, progressive disability that strikes their child during the teen years? I'd especially like to make contact with parents of dystonic teenagers.

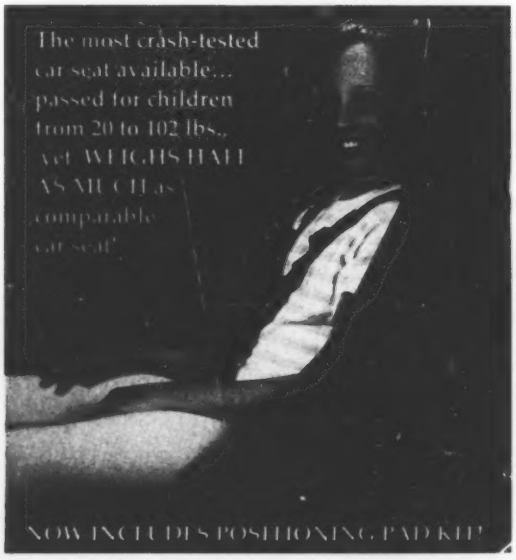
L.R.
California

*Super **Light**, Super **Strong**, Super **Safe**, Super **Simple**...the Columbia Car Seat has been the #1 choice since 1986* Thousands of Columbia Car Seats are now in use, and we have received some amazing crash stories. One grateful father in Louisiana sent a picture of his badly crumpled van and said, "My 4-year-old son escaped without a scratch, did not even break his glasses." One mother in Colorado wrote, "Thank you for making such a wonderful car seat! I really like how comfortable [my son] is in it. On Dec. 5, 1991, we were hit extremely hard on the passenger side. My 6-year-old son, a healthy 65 pounds, was not hurt at all because your car seat held him so securely."

Our years of *real world* experience give you peace of mind knowing your child is comfortable and secure in our seat!

PLUS it's lightweight, easy to use, good-looking and easy to care for!

Ask for our FREE Full Color Catalog of convenient, helpful products



The Columbia Car Seat is your best value!

- The LIGHTEST special car seat–easy to handle!
- Fits easily into ALL vehicles, no matter how compact!
- EXCEEDS all Federal safety standards!
- Approved for car, school bus and even airplane travel!
- Fits your choice of 4 stroller bases!

MEDICAL MFG. CORP.
(800) 454-6612
Dept C L, P.O.Box 633
Pacific Palisades, CA 90272

Lennox-Gastaut Syndrome

Our 22-month-old son, Benjamin, began having seizures at 10 months. Until then, he had seemed to be developing normally except that he'd always seemed quite distant and aloof. He rarely made eye contact with us. He was not interested in toys or any form of play. Recently, he began having atonic (drop attack) seizures; at one point having as many as 50 per day.

His initial diagnosis was infantile spasms, but the doctors now say he has Lennox-Gastaut syndrome. I also believe he has autistic-like symptoms. He is completely non-verbal and seems to understand only his name. He grinds his teeth occasionally. As for toys, he is only interested in tops or other things that spin.

We are searching for parents of a similar child, or anyone with a suggestion as to how I could simply get my beautiful son to look into my eyes. It is hard not knowing how to get through to him. Is there anyone out there who knows what we are going through?

D.S. & J.S.
New York

Bloom Syndrome

My two children—ages four and seven—were recently diagnosed with Bloom syndrome. Bloom syndrome is an extremely rare genetic disease in which children do not grow normally. My children are fed via G-tube while they sleep every night. Doctors tell me that my daughter will never be taller than four feet, six inches; and that my son will never be taller than four feet, nine inches. We can live with short stature, but I also understand that they are at risk for many different types of cancer, usually occurring by age 22. I would be very interested in hearing from anyone with a child who is similarly diagnosed.

C.H.
New Jersey

Werdnig-Hoffman Disease?

My daughter is 27 months old. She was diagnosed with Werdnig-Hoffman disease—also known as Spinal Muscular Atrophy, Type I—at the age of five and a half months. We are unsure if this is an appropriate diagnosis for her, because she has done extremely well and far outlived her original prognosis.

She is healthy, but her muscle tone has not improved. She has had very few respiratory infections. She has absolutely no head control and is like a rag doll. Her neck muscles are especially atrophied. She is extremely bright and talks all the time. She has no facial weakness. Her upper body is weaker than her lower body. She has very little use of her arms, but can kick her legs and pushes with them when she is laying on the floor. This is unusual because Werdnig-Hoffman disease usually affects the lower body more than the upper body. She even wiggles her body!

I would like to correspond with any parents who might have a child with a similar condition. We have met lots of parents through the spinal muscular atrophy organization, but our daughter is different from most of their children. She seems floppier but also has a lot more movement. We would appreciate any enlightening information anyone could share with us.

J.B.
Wisconsin

Arthrogryposis Multiplex Congenita

My eight-month-old daughter, Rachel, was born with two dislocated hips and clubfeet. Her arms and legs are both very contracted. Her hands are tightly clinched. She does not move her arms or legs. Rachel has been diagnosed with Arthrogryposis Multiplex Congenita (AMC).

Family Support, including **Parents Search** and **Respond**, is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published in **Parents Respond.**

Write or fax:
Parents Search or **Parents Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994)

At Devereux...
a helping hand is just a phone call away

1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle #19

Haverich ORTHOPÆDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

Circle #36

Rachel has good head control. She's very bright and talkative. She can lift her legs up by using her stomach muscles. While on her back, she can bounce her legs by using her hips. She sometimes moves her thumbs, toes and feet. Rachel sits up very well without any support. She wears splints on her feet and hands. She uses her head, nose and mouth to play with her toys.

I hope I can hear from other parents of children with AMC. I want to know how these children get around when they are older? I don't know much about this condition and would appreciate any information I can get.

A.J.
Pennsylvania

Celiac Sprue

I'm looking for another parent who has a child with celiac sprue, a digestive disease which prevents the digestion of gluten/wheat products. I'd love to hear from another parent who has a child with this condition.

S.L.W.
Florida

Myotubular Myopathy in X-linked form

We are trying to locate children with X-linked myotubular myopathy (also known as X-linked centronuclear myopathy). We have been gathering information on as many affected boys as we can locate in hopes of sparking an interest in more research. To date, we have located 20 children in the United States and one in Canada.

G.S & P.S.
Texas

Children's laughter is music to our ears.

Our dedicated staff at the Kennedy Krieger Institute is devoted to helping children and adolescents with physical, mental or educational disabilities. Through diagnosis, treatment and education, we can help find the key that unlocks the future for your child and your family.

Kennedy Krieger Institute...providing quality services for youngsters of any age with:

- Assistive Technology Needs
- Motor and Language Delays
- Metabolic & Degenerative Diseases
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

Kennedy Krieger Institute

A comprehensive resource for children with disabilities

Call us to talk about your concerns, slight or severe. We can help.

(410) 550-9400 / 1-800-873-3377
707 North Broadway
Baltimore, MD 21205

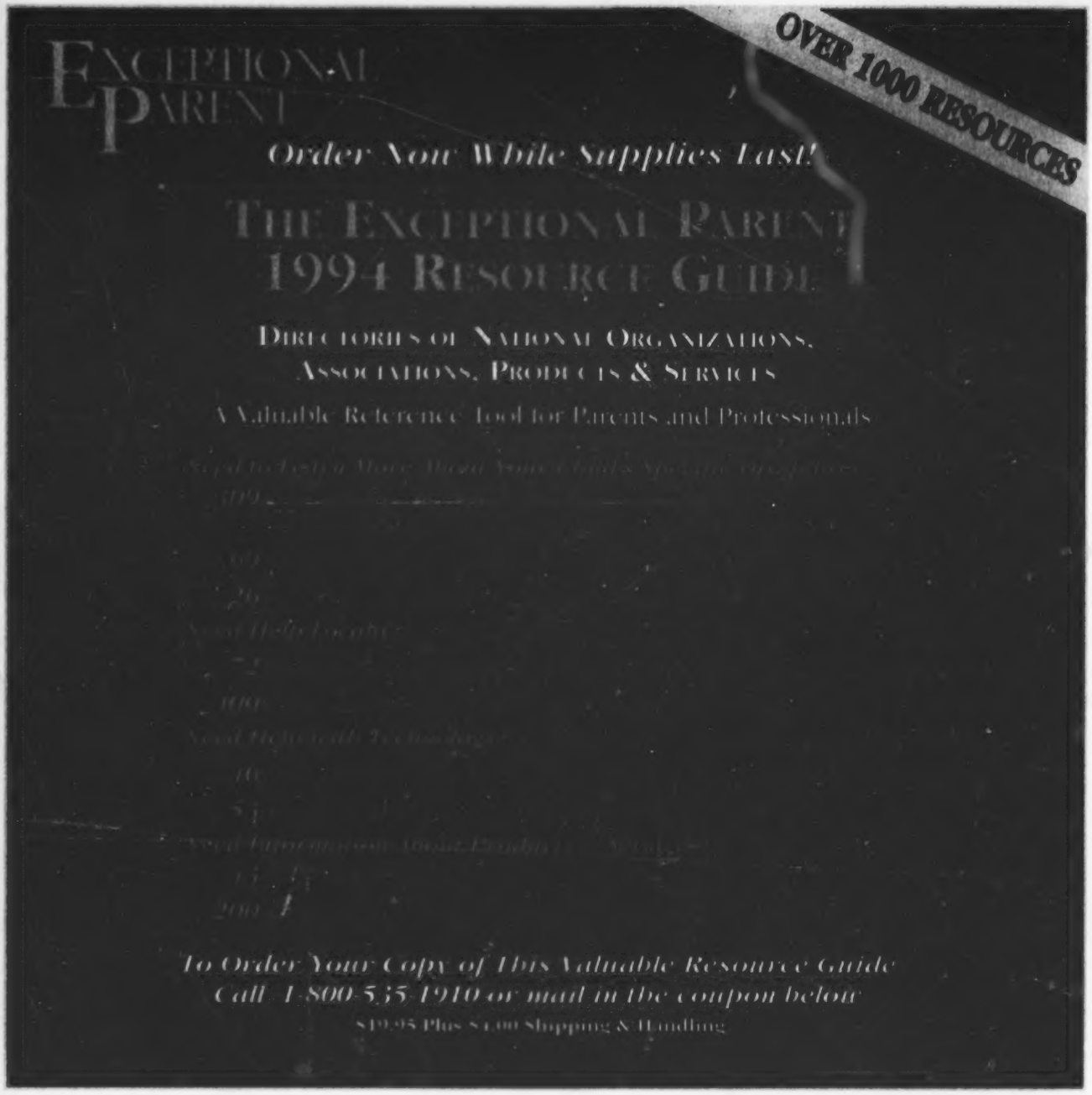
Circle #45

Young Artists Wanted

Exceptional Parent is now using children's artwork to illustrate feature articles and departments. We invite your children to share their work with our readers. Send artwork to:

Exceptional Parent
Children's Art
209 Harvard St., Suite 303
Brookline, MA 02146-5005

Put the picture's title, along with the child's name and address, on the back of submitted artwork.


EXCEPTIONAL PARENT
OVER 1000 RESOURCES
Order Now While Supplies Last!
THE EXCEPTIONAL PARENT 1994 RESOURCE GUIDE
DIRECTORIES OF NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS & SERVICES
A Valuable Reference Tool for Parents and Professionals
To Order Your Copy of This Valuable Resource Guide
Call 1-800-535-1910 or mail in the coupon below
$19.95 Plus $4.00 Shipping & Handling

Mail to: *Exceptional Parent*, Dept 94BAFC, P.O. Box 8045, Brick, NJ 08723 . . . **or call 1-800-535-1910**

❑ Send me _____copy(s) ($19.95 + $4.00 S&H) of *The Exceptional Parent 1994 Resource Guide*

❑ Check Enclosed ❑ Mastercard ❑ Visa

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Expiration Date:

Signature _____

Name _____

Address _____

City _____ State _____ Zip _____

Telephone (____) _____ Fax (____) _____

U.S. Funds Only
These prices are subject to change
Please allow 4-6 weeks for delivery
Returns must be made within 4 weeks of delivery

EP055DR

Parents Respond

Asperger's Syndrome/Landau-Kleffner Syndrome

L.N. (November/December 1993) has a five-year-old son who was recently diagnosed with Asperger's syndrome. Because of an abnormal EEG, however, doctors are now considering the possibility of Landau-Kleffner syndrome instead. L.N. and her husband were desperately searching for information about both syndromes.

While Asperger's syndrome is often referred to as "high functioning" autism, individuals with Asperger's syndrome have a less severe language disorder than those with more "classical" autism, many of whom are essentially nonverbal. However, they have impaired social interaction and relatedness—they fail to maintain appropriate social "distance," misinterpret subtle social cues and show a lack of true reciprocity in social attachment. They may have exceptional rote memory. Like most individuals with autism, those with Asperger's syndrome are visual learners but may have difficulty comprehending spoken language, particularly nuance, subtlety and abstraction.

Landau-Kleffner syndrome refers to young children who appear to be developing normally in all areas—including language—until about two to six years of age. Then, the child's language regresses as he or she develops a seizure disorder which appears to have a focus in the area of the brain concerned with language. The behavior of these children may be indistinguishable from autism. About half of these children recover language function.

For more information about autism in general, write to the Autism Society of America at their new location (7910 Woodmont Ave., Suite 650, Bethesda, MD 20814) or call their information and referral number, 1-800-328-8476.

R.J.K.
Maryland

■ My seven-year-old son, David, was diagnosed with Landau-Kleffner syndrome (LKS) at age five. I received a great deal of information from the United States Department of Health and Human Services. Information is also available from CANDLE (Childhood Aphasia, Autism, Neurological Disorders, Landau-Kleffner and Epilepsy, 4414 McCampbell Dr., Montgomery, AL 36106, 205-271-3947).

My son developed normally until age three. At that time, his language skills began to regress, and he became increasingly hyperactive. We placed him in an early-intervention program. When he was four, we met a speech and language therapist who recommended that we consult a pediatric neurologist. By this point, David's language skills had regressed to two words. He was in "his own little world" and his behavior was often unpredictable.

An abnormal EEG, his medical history and two weeks of additional testing in a hospital confirmed the diagnosis of LKS. David went through a six-month regimen of injections of ACTH. His EEG normalized, but there was no improvement in receptive or expressive speech. Around the age of five, his speech began to return. He also started to become more interested in the world around him.

Today, David is in a full-time learning support class, but mainstreamed for several subjects. He is a very bright child and loves to learn. He receives speech and language therapy four times per week. He is progressing beautifully, although his social development is behind by several years. He has emerged from "his own little world."

L.M.P.
Pennsylvania

■ The diagnosis of LKS means the possibility of recovery and a normal life; I know because my son has recovered. He is almost 10 years old, and is in a regular fourth grade class. He is an honor roll student, speaks, understands speech normally and socializes like any other child in his class. No one would ever know that he once had a problem.

J.R.
Alabama

■ I have a three-year-old daughter who was just diagnosed with LKS. My daughter talked at a very early age, walked before a year and was very advanced in most areas.

Presently, she is unable to speak or understand verbal language. Sometimes, she says single words; other times, she is mute. Her problem-solving skills are good, as are her fine and gross motor skills. It has been very frustrating for her to be unable to communicate. She does not understand what is happening to her.

L.A.H.
Massachusetts

Parents with Disabilities

C.L.B. (November/December 1993) has a neuro-muscular disease, and is also the parent of two preschoolers, one of whom is a four-year-old boy with autism. Her situation has become even more difficult since her husband passed away last spring. She wondered how other parents with physical disabilities coped with everyday problems.

I am a mother with multiple sclerosis and four boys aged eight, five, three and one. My eight-year-old son was recently diagnosed with Attention Deficit Disorder, but his true condition may be closer to Tourette syndrome. My five-year-old son was born with Down syndrome, and has developed insulin-dependent diabetes, lactose intolerance, celiac sprue and intestinal malabsorption syndrome. I also feel emptiness, frustration and anger when no one seems willing to help or understand.

We have tried to get in-home medical respite for years and cannot. I thought there was no one else with similar circumstances, but when I read your letter I cried.

M.J.
Illinois

■ Your letter touched my heart. I can offer no advice or suggestions—only empathy and my story. *Exceptional Parent* has done a wonderful thing in making me aware that my family is not alone.

Our second son, Daniel, was born with a rare genetic metabolic defect. He was medically fragile with multiple severe disabilities including profound retardation and blindness. He required around-the-clock care for his five-and-a-half years of life.

GM MOBILITY PROGRAM

Maintain your daily independence through the General Motors Mobility Program for the Physically Challenged.

It starts with a toll-free call to our GM Mobility Assistance Center. We'll identify your local driver assessment centers, list your area's installers of adaptive driving devices or vehicle modifications and suggest which GM cars and light-duty trucks might work best for you.

Next, whether you buy or lease a new GM vehicle or dealer demo model, we'll reimburse you for the cost of adapting it–or for the reinstallation of your own adaptive equipment–up to $1000.

(Reimbursement for leased vehicle adaptation available only upon lessor's approval to adapt vehicle.)

We're making every day Independence Day.

Qualified customers can finance the cost of the vehicle and any modifications through GMAC in a single transaction at participating dealers.

The people at GM, and GM dealers nationwide, know how important mobility is to your everyday life. Call us today. Or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer and find out how the General Motors Mobility Program can help make every day Independence Day for you.

- **Call toll-free: 1-800-323-9935 (TDD users: 1-800-TDD-9935)**
- **Information on driver assessment centers and adaptive equipment installers**
- **Reimbursement of adaptation costs, up to $1000**
- **Financing available through GMAC**

General Motors

177

Despite all his problems, he was a happy and charming boy—far exceeding any goal or life expectancy ever mentioned. He met his match last April in the form of mononucleosis and died in my arms.

I developed a non-specified connective tissue disease—an arthritis-type condition—during my pregnancy with Daniel. It caused loss of strength in my joints. It is in my fingers, wrists, elbows, shoulders, hips, knees and feet.

With this condition, Daniel's care was difficult. I had no secret for getting through my days. I pushed myself to the breaking point daily. My love and devotion to Daniel made it all possible because I never knew if that day would be his last. We received only 15 hours of nursing respite care per month.

Our youngest daughter, Rachel, was the first child in the world to be tested prenatally for Daniel's condition. Her birth helped our family beyond belief. We all had something to look forward to—her future. And she gave her older brother, Nathan, someone with whom to share his burdens.

Daniel's life was very hard for most of our friends to bear. We lost most of our friends. As you have probably also experienced, people become uncomfortable with such misfortune and really distance themselves from it.

We will think of you often and please find comfort in that. It is all we can give, but it is given with understanding and love.

G.R. & B.R.
Oregon

Undiagnosed

W.J.R. & T.R. (November/December 1993) are looking for a child who is similar to their 11-month-old son, Dakota. Dakota is developmentally delayed and has dysmorphic features which include slightly protruding, wide-spaced eyes, low-set ears, nose with flattened bridge, high palate and simian-creased left palm. His heart has an atrial ventricular valve dysplasia with a possible mild AV-valve stenosis. Extensive medical and genetic testing has failed to yield a diagnosis.

Our 13-month-old son, Michael, has so many of the same characteristics as Dakota that I had to write immediately! Michael is developmentally delayed. He has widely spaced eyes, low-set ears which tilt slightly to the rear, flattened bridge, high palate, low muscle tone, broad hands and toes. We know of no heart problems, but this area of his body has not been screened. He was born with a slightly malformed penis (hypospadias) that was surgically corrected.

At this point, Michael's neurologist believes that he has Opitz-Frias syndrome (also known as "G syndrome"). Yours is the first case I have heard of that is so similar to mine. I also think it is interesting to note that we both live in New Jersey; this just adds to my personal theory concerning environmental factors.

J.P. & D.P.
New Jersey

■ You are not alone! After reading your letter, I just had to write to you. Dakota seems very similar to my son, Michael, who is also "undiagnosed."

Michael is 15 months old and has features that sound very similar to Dakota's. Michael has some additional problems such as bilateral atresia of the ear canals—with resulting hearing loss, unusual defects of the left eye, and atrial-septal heart defect. He was also born with an omphalocele (his intestines were outside of his body) that was repaired by surgery at birth.

Michael also has had every conceivable test. All have been normal including several high resolution chromosome analyses. Of course, this disappointed the doctor who was absolutely convinced that Michael had Down syndrome because of his facial features and the simian creases on his hands.

Like Dakota, Michael is developmentally delayed. He has been assessed at the six- to seven-month level in all areas. He is involved in early intervention and has already far surpassed what the medical field expected of him. We are proud of his every accomplishment, and are convinced that he will surprise us all.

I was most compelled to write to you because we also live in New Jersey. We have "toured" hospitals in New Jersey and Pennsylvania, searching for answers. The uncertainty of the future is the hardest thing to deal with. We too are desperate for a diagnosis.

K.C. & M.C.
New Jersey

Leber's Congenital Amaurosis

R.S. & V.S. (November/December 1993) are the parents of five-year-old Courtney who has Leber's congenital amaurosis. In addition to visual problems, Courtney has mild retardation with neurological and speech problems. She is still in diapers and drools a lot. Her parents did not know of other children with Leber's who have problems in addition to vision.

We are the parents of a four-and-a-half-year-old boy who has been diagnosed with "complicated" Leber's congenital amaurosis. We don't know Jon's visual acuity, but suspect he is in the 20/100 range. He is very interested in books with large print, and he is able to manipulate a computer. He uses a white cane for better mobility in outdoor or unfamiliar surroundings. Jon is also profoundly deaf and was diagnosed with "floppy baby syndrome" (hypotonia) when he was about six months old.

At about six months of age, we enrolled Jon in a "generic" early intervention program and registered him with the New Jersey Commission for the Blind. When he was 14 months old, we transferred him to an early intervention program designed specifically for children with visual impairments.

Shortly after beginning this program, Jon's hearing was tested. Just before his second birthday, we learned he was deaf. So we found another early intervention program—this one for deaf and hearing impaired children—and Jon went to both programs for one year. It was a hectic pace, but certainly worth it! At the program for visually impaired children, he learned to use the vision he has and developed orientation and mobility skills. At the program for hearing impaired children, he began to learn sign language and develop interpersonal skills. He is now in his second year of preschool at the school for deaf and hard of hearing children, and we still receive support services—a teacher of the visually impaired, orientation and mobility instruction, computer specialists and physical education consultant—from the Commission for the Blind.

Jon has come such a long way in his short lifetime and we are so very proud of his accomplishments! Nonetheless, we often feel that his diagnosis has isolated us from both blind

NEW IMPROVED QUICKER MIX FORMULA
PROUDLY MANUFACTURED IN THE U.S.A.

To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, free samples and information where DIAFOODS THICK-IT may be purchased, call (800) 333-0003.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

The joy of anticipation was all over his face...Troy's dad was taking the training wheels off his bike. His dad helped him get started...then, he let go...and Troy was doing it, he was riding all by himself!

Troy's father knew that sometimes the hand that helps most is the hand that lets go. So did the parents of Sean, a young boy with multiple disabilities.

Sean was 13 years old when he arrived at Heartspring's residential school. He was unable to tolerate being around a lot of people. Crowded rooms or noisy hallways frightened him. He couldn't seem to participate in the real world.

From the very beginning, Heartspring staff worked with Sean's parents, school districts, and other professionals, setting goals so he could gain the independence he needed and return to his home community.

Now, four years later, Sean attends public high school classes for a couple hours, then goes to work at a restaurant on the campus of a local state university. He has learned to tolerate walking in hallways that have over 1,000 students on their way to class! Currently, staff are working on other needs Sean has to ease his transition from Heartspring to his home community.

Like Sean, all children who enter the doors of Heartspring are guided to discover a greater sense of independence, confidence, and the ability to reach for their potential. Our individualized programs and personal care help children with disabilities make it through many of the challenges they face growing up.

If you know a child who needs help making a transition into the real world, call Heartspring today: 1-800-835-1043.

HEARTSPRING℠
A LIFESKILLS LEARNING CENTER
2400 JARDINE DRIVE WICHITA • KANSAS 67219-4699
316 • 262 • 8271 800 • 835 • 1043

Formerly the Institute of Logopedics

Circle #38

and deaf communities. It's hard to relate when Jon doesn't naturally "slide" into either group. Though legally blind, he has good usable vision and will probably read large print. On the other hand, his deafness prevents him from using many of the other aids for visually impaired individuals such as radios, books on tape and talking computers. We have felt more at home with the deaf community, although Jon's vision impairment complicates his communication skills.

I also have met several parents of children with Leber's and most of these children, as you have found, have only vision impairments. I do know of two other families whose children have "complicated" Leber's, but these complications do not include deafness. I belong to parent organizations for the deaf, blind and deaf/blind, but I have not yet met anyone with a child like Jon.

K.G & J.G.
New Jersey

■ I have an eight-year-old daughter with Leber's congenital amaurosis. Lauren seems to have much more involvement than your daughter. We know that Lauren has usable vision but don't know how much. Like Courtney, her vision has improved since she was younger. Lauren is non-ambulatory and non-verbal. She has severe mental retardation. She has had intractable seizures since she was about two-and-a-half years old.

You mentioned problems with drooling and diapers. Lauren always drooled a lot but in the last two years, this has improved a lot through no specific intervention. Lauren wears pull-up diapers. A teacher suggested we try potty training about a year ago. I thought she was crazy, but we tried it. It was really more like "potty timing," but Lauren does surprisingly well considering that she cannot communicate her need to go. The pull-ups are much easier to put on and take off than diapers. Since Lauren can stand well with balancing support this really has made life easier.

G.F.
New Jersey

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*. BEST BUY!

*US funds only. Canada $30 per year. Other foreign countries $33 per year.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 34C

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*. BEST BUY!

*US funds only. Canada $30 per year. Other foreign countries $33 per year.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4-6 weeks for delivery. 34C

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

See reverse side for subscription details

HEAD OF THE CLASS.

Introducing the Zippie 2: the chair that not only grows with kids, but goes with them too!

At the heart of the Zippie 2 is a completely new frame design, with a folding back and crossbrace. So the Zippie 2 folds flat for easy transportability to all the places kids need to go. School. Grandma's house. The ball game. All with a ride that feels more like a rigid than a foldable.

But of course, it wouldn't be a Zippie if it wasn't growable. So the Zippie 2 has an innovative new growth system, with a replaceable folding crossbrace to increase width, and an adjustable seat back that grows in depth. The Zippie 2 gives kids the fit – and the options – they need, throughout their childhood years.

The Zippie 2 from Quickie. For kids who are on the go, and on the grow.

Vicki Bertoldi, Parent

"The Zippie 2 is perfect...not just for Brooke, but for the whole family. It's easy to adjust for her growth and folds flat enough to fit anywhere."

QUICKIE

The RealChair People.

SUNRISE MEDICAL

QUICKIE

Quickie Designs Inc.
2642 Business Park Ave.
Fresno, CA 93727-1328
(209) 292-2171
(800) 456-8166

Circle #92

© 1991 Sunrise Medical, Quickie Designs Inc.

DOING WHAT WORKS BEST

"Wheels" give Brian the freedom to move ahead.

by Kathy Olsen

Standing beside me in the church parking lot, an acquaintance asked, "Is he pretty much confined to that thing now?"

The words stung, and I was immediately on the defensive. "He" was our five-year-old son, Brian, who has spina bifida. "That thing" was his black and red sports wheelchair. "Confined" usually means trapped.

I could have asked my friend to call that "thing" a wheelchair. I could have pointed out that Brian is far less confined in his chair than out of it, because his walking is exhausting and very slow. I could have said that he never feels freer than when he has his "wheels." They're fast, they're sleek, they're fun—at least, that's what Brian's words and actions tell me. I could have said all that, but I didn't. My friend's casual question was like a pronouncement of failure.

I now realize that the failure I felt at my friend's words that day just wasn't real. Choosing to use a wheelchair is not a failure. Failure means failing to do what works best.

When Brian was born on June 16, 1982, with a myelomeningeocele, we didn't realize that spina bifida would be the lesser of his problems. When he was one month old, he began having episodes of apnea—he stopped breathing when he cried. The apnea turned out to be a symptom of Arnold-Chiari syndrome, a malformation of the brainstem. Brian underwent three major brainstem surgeries in his first three years. This caused additional developmental delays, upper-body weakness and range-of-motion loss in his arms.

Unrealistic Expectations

By eighteen months, Brian was standing with support, and we planned to start gait training when he was two years old. My expectations for his progress were based on my knowledge of older children who had waist-level spinal lesions like his. I saw these children getting up and down from the floor and walking. I believed that Brian would follow a similar pattern. Naively, I thought through the timing of having a second child—Brian would get braces at this time; he'll ambulate at some later time; after that, we could have a baby.

Perhaps it was over-eagerness, or hesitation to make predictions. Whatever the cause, professionals never gave us any lower, more realistic expectations to counter our observations of other children with spina bifida. I understand that low expectations may hinder progress, but unrealistically high expectations, as we learned, may lead to burnout and failure.

A torturous year

When Brian started gait training, he was a highly verbal, friendly and cheerful two-year-old. The next year of our lives was tor-

turous. There were no qualified therapists in our area. We began by going to a city two hours away and working with a good pediatric therapist every day for a week; after that, we were on our own. I became Brian's primary therapist.

We worked every day for three months before Brian took an unassisted step. These daily therapy periods included crying, episodes of apnea and my frustration and anger. I thought that his slow progress was my fault. I thought that I had to put Brian through an emotional wringer to help him "work through the fear." I wish I could go back and erase some of those experiences.

Of course, there were happy moments. Every flicker of success brought overreactions of joy and praise. I baked a cake and invited friends over to celebrate those few, hard-won steps.

After six months, Brian could take three unsteady steps. He showed much courage, but his fear and total lack of desire to walk were mountains we had to climb daily. After a year, he walked fifty feet, but it required fifteen minutes and constant coaxing.

Blowing the Whistle

When Brian turned three, the consulting therapist suggested teaching him to get up and down from the floor. Almost every time we went through this exercise, Brian would cry and have apnea. As his "therapist," I felt driven to work through this agony, but my motherly instincts wanted to protect him.

Finally, the truth became obvious. After three years of reading—in *Exceptional Parent* and elsewhere—that parents need to make the final decisions regarding their child's treatment, I realized that it was time to blow the whistle. It had come down to a choice between being a good therapist or a good mother. I was sure of my decision; I was ready to throw the braces and walker out the window.

The therapist convinced me to compromise. She had seen children change their attitudes and start making rapid progress when they turned six or seven. We agreed to step back to a more comfortable schedule and "hang on." We stopped working on new skills and cut down on Brian's walking time, but kept using the standing table in order to strengthen his bones.

Braces and Burnout

Our experience with burnout taught us some very important lessons:

• *Parents decide:* With therapy, as with every other aspect of the child's treatment, we are the best judges.

• *Therapists advise:* Physical therapists—like all professionals—have a responsibility to encourage, to motivate and even to press the parents; but they are limited in their knowledge of the whole child. Consider the therapy schedule as advice, not law.

• *Use a therapist, or be prepared:* Therapy must be reinforced at home, but try to have a qualified physical therapist do the primary work with the child. If you must be both therapist and parent, plan carefully. Know how you will approach difficult tasks, when you will push and how to make it a positive experience for the child.

Top: 10-year-old Brian singing "Splish Spash" at 1992 Talent Show. Center: Brian, at age 6, pictured at Birdwell School's Western Day. Bottom: Brian, age 11, with brother Mark, 9, displaying his prize catfish.

• *Blow the whistle:* When the child is suffering undue stress, take responsibility for stopping or changing the therapy regimen.

• *Take one step back:* For Brian, stepping back to a less stressful routine boosted his confidence. Continually asking for "just a little bit more" can make a child feel that he is never quite good enough.

• *Let the child initiate progress:* Our scaled-back therapy regimen gave Brian an opportunity to begin a new challenge when he felt ready, rather than always feeling one step behind.

• *Communicate with the therapist:* The therapist will never have a complete picture of your child without your feedback. Communicating our stress better and sooner would have saved us some grief.

• *Take time to live:* With all the medical, dental, optical and therapy appointments Brian faces, it's important for us to emphasize that he should take time to enjoy life, even if that means slowing down the therapy process.

• *Affirm, Affirm, Affirm!* We continually tell Brian and ourselves that we are doing our very best with a very difficult job.

Moving Forward

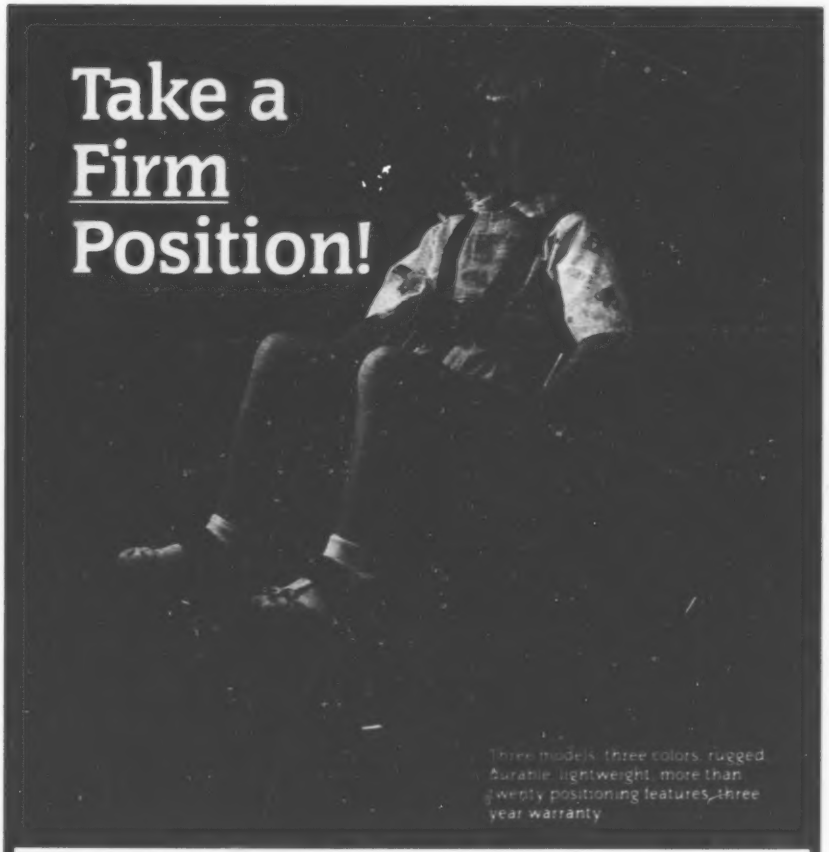
For the last five years, Brian has been mainstreamed in a public elementary school. He maintains above-average grades and sings in the annual school talent show. For the first three years, he walked in braces briefly during adaptive physical education classes and stood in a standing table for one hour a day. In third grade, realizing that walking was still too slow and demanding to be practical, we decided to continue having Brian stand for one hour a day at school while using a wheelchair for all mobility. That's the way he likes it, and it has worked very well.

Interestingly, as we were choosing the pictures to accompany this story, Brian eliminated all the pictures that showed him in his braces. He explained that he would be embarrassed for others to see him with braces and a walker. "They would think there was something really wrong with me," he said. So much for projecting our viewpoints onto our children!

The bottom line is that Brian has never had any desire to ambulate with braces, and still doesn't. He seems to know what he can do and is satisfied with that. Because of his daily standing, he maintains the potential to walk if he changes his mind. We endangered that potential, however, by driving ourselves too hard.

Meanwhile, Brian pitches for his class kickball team, collects baseball cards and dreams of becoming a radio sportscaster. For us, taking one step back brought us two steps forward—happier and more ready to face the challenges ahead. ■

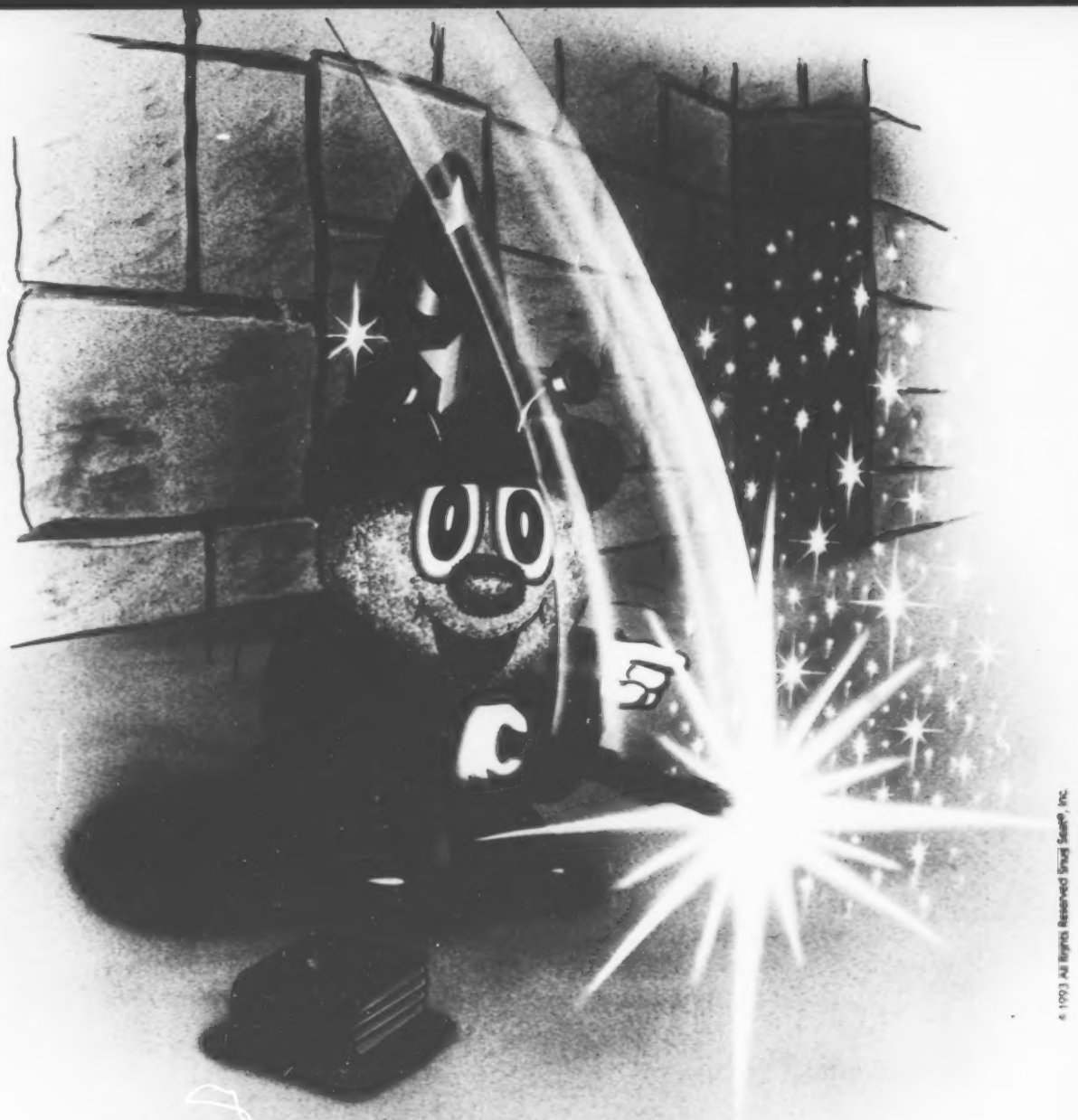
Kathy Olsen is a writer and speaker who lives in Texas with her husband, Lloyd, and two sons, eleven-year-old Brian and nine-year-old Mark. She is the author of Silent Pain: Finding God's Comfort for Your Hidden Heartaches *(NavPress, 1992; Call 1-800-366-7788 for ordering information.) and numerous articles. Kathy volunteers in her church and at the private school her sons now attend.*


Take a
Firm
Position!
Three models, three colors, rugged durable, lightweight, more than twenty positioning features, three year warranty

"Convaid Cruisers" . . . firm positioning buggies for children with special needs.

Your child's comfort is assured by the care and construction that goes into every Convaid Cruiser because the patented fold of the Cruiser *gives your child firm positioning*. In fact, the more your child's body weight presses down, the firmer the upholstery becomes. When you travel, the Cruiser folds easily to fit into your trunk or backseat.

Convaid PRODUCTS INC
P.O. Box 2458 / Palos Verdes, California 90274
310-539-6814 / 1-800-552-1020 TOLL FREE
FAX 310-539-3670
Circle #16



© 1993 All Rights Reserved Snug Seat®, Inc.

This WIZARD® Will Amaze You!

Comfortable and fully adjustable, the WIZARD offers tilt-in-space, a fully reclining back, and elevating legrests....A magic act that no other pediatric wheelchair can perform, and it's standard with every unit!

The WIZARD easily separates into two components weighing less than 20 lbs. each....Mom can effortlessly load the WIZARD into the trunk!

The WIZARD offers these advantages

- Made of strong steel tubing, the durable WIZARD frame is guaranteed for the Lifetime of the User.
- Grows with your child from age 1 to 10 without having to purchase an expensive growth kit.
- Tackles any terrain with it's heavy duty 8"x2" front caster tires.

The Wizard
PEDIATRIC WHEELCHAIR
BY SNUG SEAT®

1-800-336-7684
Fax 1-704-847-9577
In Canada 1-800-667-3422

By SNUG SEAT®, INC. Providing Technologies For Mobility, Positioning & Transportation Since 1987

Circle #69

The best wheelchair lift you've never seen: MIRAGE™

For Your Volkswagen EuroVan®

The best feature on our newest wheelchair lift is invisible. When the patented Mirage lift is not in use, it stows away in a hidden protective enclosure beneath the floor of your EuroVan. it's out of mind, leaving the entire doorway clear and maximizing your floor space.

Mirage is easily available when you need it, letting you raise, lower, stow and deploy quietly with the touch of a button. Its aluminum-and-steel construction provides strength and durability. And when Mirage is out of sight,

Convenience like this is hard to find...unless you know where to look. Call Ricon at **1-800-322-2884** or your VW® dealer for more information on the Mirage lift.

Ricon Corporation
12450 Montague St.
Pacoima, CA 91331

Tel. (818) 899-7588
1-800-322-2884
Fax (818) 890-3354

Ricon Canada Inc.
14750 Gouin Blvd. W.
Pierrefonds, Quebec
Canada H9H 1B2

Tel. (514) 626-0261
Fax (514) 626-0264

RICON

Innovation in Mobility

Ricon U.K. Ltd.
153 Bennett St.
Ardwick, Manchester
United Kingdom
M12 5BW

Tel. 061-274-3711
Fax 061-274-3706

Ricon Scandinavia AS
Stanseveien 27
N-0976 Oslo
Norway

Tel. 22 16 70 90
Fax 22 16 60 90

Circle #65

Wheeled Mobility Selection:

A GUIDE FOR PARENTS

Quickie Kidz wheelchair, manufactured by Quickie Designs, Fresno, CA.

In some respects, a wheelchair is like an automobile or a pair of shoes. It provides the interface between a body and the world around it. Like shoes, a proper fit is essential to enable a child to maximize her or his potential and feel comfortable moving around in the world. Like a car, design factors can take into account the user's personal needs and interests.

Thirty years ago there would have been no need for an article on wheelchair selection. Someone needing a wheelchair would have gone to a doctor to get a prescription for a wheelchair. That chair would have been fairly standard in size and appearance—a heavy, metal chair with black or dark green upholstery. Nothing else was available.

Now, thanks to the variety of available wheelchairs and options, selecting the appropriate wheelchair can be a bewildering task. This article will provide information about wheelchairs, and describe wheeled mobility options in the marketplace today. This article will not discuss the variety of strollers that are available for younger children or for children who are unable to propel a wheelchair independently.

Considering Individual Needs

It is impossible to select an appropriate chair until a child's needs have been assessed. This involves determining the level of necessary assistance and considering how the wheelchair will be used.

Wheelchair prescribers—occupational therapists, physical therapists, or other members of the clinical team—can determine how much assistance the wheelchair should provide. While some children with quadriplegia, for example, can only use powered wheelchairs, others may find that they are able to use a manual wheelchair or a powered scooter. These alternatives may more appropriately fit into the family's lifestyle and are less expensive.

It also is important to determine how the wheelchair will be used. Will it be used indoors, outdoors and during transport in a van or car? Some children use a manual wheelchair in their homes, but use a powered chair outside and in school. For many families, the ability to fold a wheelchair or take it apart easily for traveling in a car is important.

The "Right" Chair

Once a child's needs have been determined, the next step is to choose the "right" chair(s). Parents of a child who is new to using a wheelchair may wish to talk with more experienced parents about their likes and dislikes. There is nothing like practical experience to provide feedback on specific features that may be desirable, as well as those that should be avoided. Prescribers and medical equipment dealers, who often receive feedback from previous clients, can also be good sources of information. Finally, there are some written resources on wheelchairs now available (see below), and ABLEDATA, a database with information on more than 19,000 products for children and adults with disabilities, is a good source for information on specific wheelchairs (see page 56).

Stroller manufactured by Convaid Products, Torrance, CA.

Wheelchairs come in many sizes, shapes and varieties to meet the diverse needs of a multitude of users who have differing levels of physical abilities and varying interests. Children with sufficient upper body strength often prefer to use a wheelchair that is propelled by arm strength, or what is called a manual wheelchair. Some children are unable to propel a wheelchair with their own arm strength. In such cases, they may prefer—or require—a wheelchair powered by batteries.

Wheelchair Components

- *Frame:* The development of new, lightweight materials for wheelchair frames has been one of the biggest breakthroughs in modern wheelchair technology. In contrast to the days when stainless steel was the only frame material available, today's wheelchair frames may be made of chrome, aluminum, airplane aluminum, steel tubing, an alloy of chrome and lightweight materials, or other lightweight composite materials. The type of material used to construct the frame affects the overall weight and strength of the wheelchair.

  The two most common types of frames currently available are rigid frame chairs—where the frame remains in one piece and the wheels are released for storage or travel—and standard cross frame chairs which are foldable for transport or storage.
- *Upholstery:* Wheelchair upholstery must withstand daily use in all kinds of weather. Consequently, manufacturers provide a variety of options, ranging from cloth to new synthetic fabrics to leather. Many manufacturers also offer a selection of upholstery colors—everything from black to neon—to allow for individual preferences.
- *Seating System:* Since seating is often chosen on an individual basis, seating systems are usually sold separately from the wheelchairs themselves. However, some wheelchairs include seating and postural support systems. When selecting a wheelchair and seating system, it is important to ensure that the two components are compatible.
- *Brake Type:* On a manual wheelchair, "braking" is accomplished by applying the hands to the wheels. However, "parking brakes" or wheel locks are available in several different designs, and can be mounted at various heights for easy use.
- *Wheels/Tires:* Most wheelchairs use four wheels—two large tires at the back and two smaller casters at the front. The standard tire used for the rear wheels on

Tire Options for Wheelchairs

Mag	Tires with oversized widths.
Off-road	"Knobby" tires with deep grooves designed to provide better traction on unpaved surfaces.
Pneumatic	Tires with air-filled tubes, similar to racing bicycle tires.
Radial	Tires reinforced with steel, similar to radial car tires.
Semi-pneumatic	Tires made from a combination of a solid rubber and air-filled tubing. Designed to reduce the possibilities of flats and to cushion the ride.
Solid	Tires without air spaces or tubes. Designed to be "flat-free," but may provide a less smooth ride.

LIFE

CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL® PEDIATRIC 3-WHEEL, RWD SCOOTER

The **REGAL PEDIATRIC** was ergonomically designed to meet the special needs of your child. The **REGAL PEDIATRIC** offers these exclusive Bruno features: Custom Contoured, Adaptable Seating for superior lateral, thigh and lumbar support; 23 hardpoints in the seatback for the attachment of various support devices; stand platform for exceptional legroom; **E-Z-TILT™** Tiller with all driving adjustments selectable from the seated position and overall Proportional Sizing™ for your child's specific requirements.

SCOOTER-LIFT JR® AUTOTRUNK LIFT

At Bruno we help eliminate the burdensome task of transporting your child's mobility aid. We make **FOURTEEN DIFFERENT KINDS OF LIFTS** for nearly any brand of scooter or wheelchair, and they can be installed in cars, vans or trucks. Bruno can help your child get around easier and make traveling a truly enjoyable experience.

CURB-SIDER® SCOOTER & WHEELCHAIR LIFT

Bruno's unique, low cost, battery-powered **ELECTRA-RIDE** Stair-Way Elevator can help your child get up and down stairs, easily and comfortably. No special wiring is needed and **ELECTRA-RIDE** will operate even if there's a power outage. Seat-Belt, Two Remote Call-Sends, Adjustable Foot Plate with Safety Sensor, Full 45-90 Degree Swivel top and bottom, including Contoured Seat, are standard. To give your child's journeys security and peace of mind.

ELECTRA-RIDE™ STAIRWAY ELEVATOR SYSTEM

BRUNO INDEPENDENT LIVING AIDS

WISCONSIN MANUFACTURER OF THE YEAR AWARD

SPECIAL AWARD INNOVATION 1988

MANUFACTURER OF THE YEAR 1991

BRUNO INDEPENDENT LIVING AIDS, INC.
1780 EXECUTIVE DRIVE PO BOX 84
OCONOMOWOC, WISCONSIN 53066

CALL 1-800-882-8183 TOLL FREE OR 1-414-567-4990 FAX 1-414-567-4341

Circle 68

Proving good looks, convenience and proper positioning work wonderfully together.

kid-EZ. Adjustable High Chair Base

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle #46

most wheelchairs is a pneumatic tire—a tire with air-filled tubes similar to those found on racing bicycles. The standard size for the large wheel is 24 inches, although smaller and larger sizes are available. Many manufacturers also offer other types of tires at extra cost. See "Tire Options for Wheelchairs" on page 24.

Stroller manufactured by Kid-Kart, Belgrade, MT.

- *Footrests:* For rigid frame chairs, footrests usually are incorporated into the frame. Cross-brace folding chairs often have footrests that can swivel and/or be removed.
- *Armrests:* Many lightweight manual chairs are designed to be used without armrests. This makes it easier for the user to roll up to a desk or table, and many active wheelchair users prefer the streamlined look of a chair with no armrests. Armrests can be helpful, however, if the user has difficulty with upper body balance while seated.

Manual Wheelchairs

Because the wheelchair market is changing so rapidly, there is no universally accepted terminology to describe the various kinds of manual wheelchairs. Most manual wheelchairs sold today, however, can be placed in one or more of the following categories:

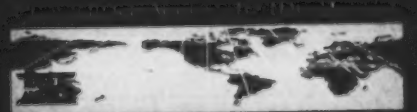
- *Lightweight/Sports Chairs:* For a child with good upper body capabilities, the most popular type of wheelchair for everyday use is the lightweight manual wheelchair. Lightweight chairs provide maximum independent movement with minimal effort. Many children also prefer the sportier look of the lightweights.
- *Standard/Everyday Chairs:* A standard wheelchair is characterized by a cross brace frame, built-in or removable arm rests, swing-away footrests, a mid- to high-level back, and push handles which allow non-occupants to propel the chair.
- *Child/Junior Chairs:* Children and young adults need chairs that can accommodate their changing needs as they grow. In addition, it is important that wheelchairs for children or teens be adaptable to classroom environments and be "friendly-looking" to help the user fit more readily into social situations. Manufacturers are becoming increasingly sensitive to these market demands and are attempting to address them with innovative chair designs and a variety of "kid-oriented" colors and styles.
- *Specialty Chairs:* Because of the diverse needs of wheelchair users, wheelchairs have been designed to accommodate many lifestyles and user needs. Chairs that can be propelled by one hand are available for children who have paralysis on one side. Rugged, outdoor chairs are available for outdoor activities. Aerodynamic three-wheeled racing chairs are used in racing events. Manual

BRAUN

THE ANSWER TO ALL YOUR MOBILITY NEEDS.

ENTERVAN™ VAN LIFTS

U



1-800-THE LIFT

193

Do it yourself growth chair...

...lets you easily adjust it in seconds for growing children or large adults. Light weight, rugged construction. At home or in sports, the Maxi is useful everywhere!

You have to see this dream machine to believe it. Over a quarter-million dollars for development. User designed. User tested. Now available for all! Consider its features:

Wheeling Free's Maximum Mobility Machine weighs only 25 lbs, yet carries over 250. Go down 6-inch curbs without help! Modular disassembly for easy transportation. Adjustible width, seat height, foot rest, etc. Airplane aisle access and sports stability. Up to 12 degrees wheel camber. Soft-riding, easy rolling airless urethane tires. Precision, sealed wheel bearings. Off-road packages for parks and beaches. Adjustable, breathable upholstery for maximum personal comfort. Adjustable height push handles.

We wish we had more room here to tell you about ALL the great features. Amazing standardized design allows over 40 easy adjustments to let you get the most out of your Personal Mobility Machine. Maxi is the ultimate in high tech American-made wheelchair quality and comfort.

Call now for the rest of the story and special discount (800).484-9793 code 1600

Warranty and service: Lifetime warranty on frame and one year warranty on wheels and upholstery. Standardized design makes service available at most wheelchair dealers.

Circle #165

chairs that raise the user to a standing position are available for children who need or want to be able to stand. Generally, these and other specialized chair designs are manufactured by independent wheelchair manufacturers to meet the needs of specific target markets.

- *Institutional/Nursing Home/Depot Chair:* The least expensive type of chair available—an institutional chair—is designed for institutional usage only, such as transporting patients in hospitals. Since it is not fitted for a specific individual, it is not an appropriate alternative for anyone who desires independent movement.

Cost

Manual wheelchairs range in cost from approximately $500 for an institutional chair, to more than $4000 for a customized lightweight wheelchair with a number of options. Most lightweight manual chairs cost between $1800 and $2800. This price range is not intended, however, to suggest an "appropriate price" to pay for a wheelchair for any specific individual. Special accessories or customizations required to accommodate specific disabilities, for example, could put the actual purchase price much higher.

Powered Wheelchairs

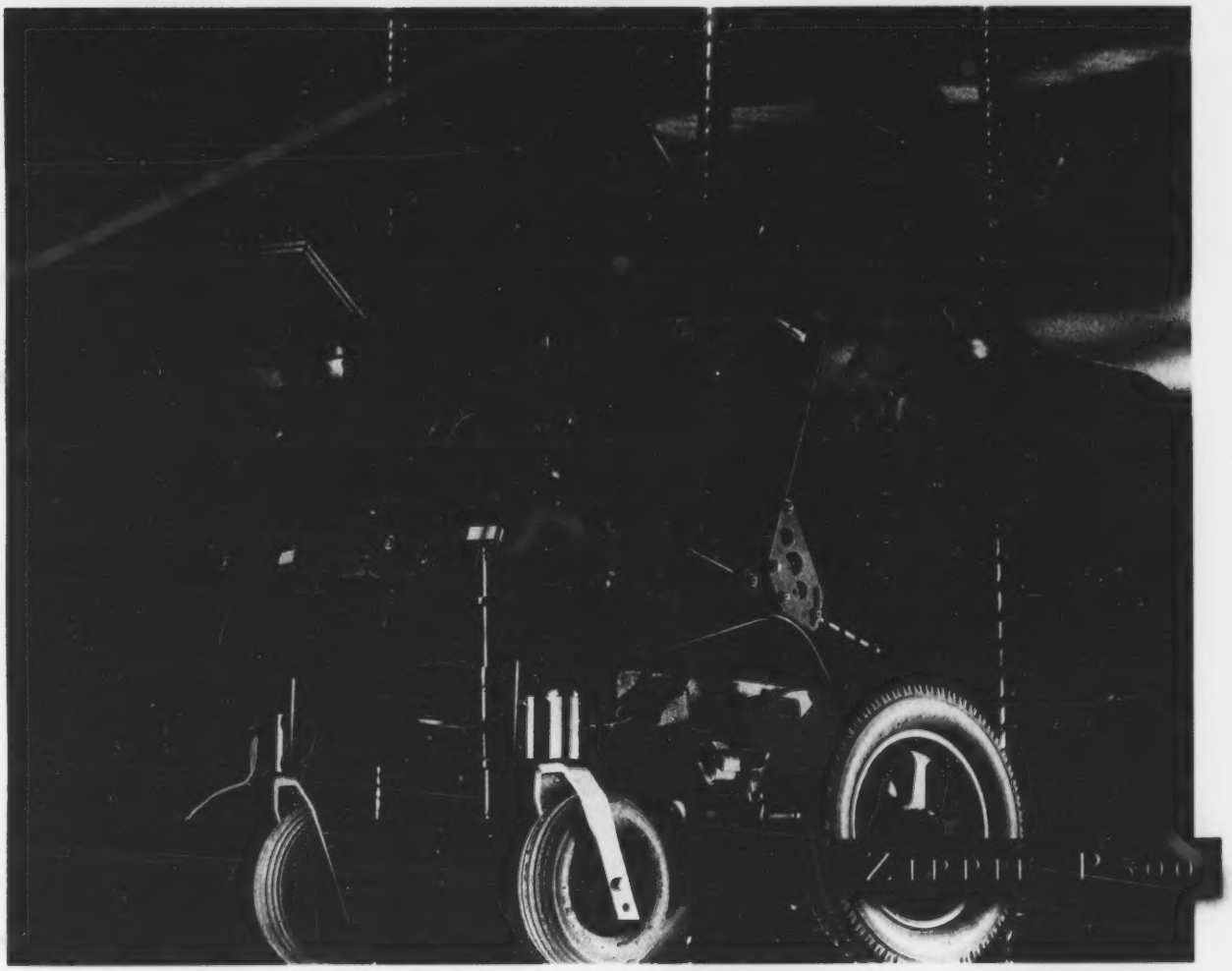
Two basic styles of powered wheelchair are currently available. The traditional style looks like a standard manual wheelchair that has been reinforced to carry the extra weight of a power and control system. Typically, such wheelchairs are powered by a battery that is attached underneath the seat. Another style is a platform-model powered wheelchair in which the seating platform is located atop a power base. A variation on the power base concept is a chair that includes built-in lifts to allow the user to raise and lower the seating platform.

The selection process for a powered wheelchair should include evaluation of the child's physical status and abilities, and usage requirements. Physical considerations include posture, strength, sensation, visual acuity and perception, and the ability to learn how to use the wheelchair safely. An evaluation should consider use of the wheelchair in everyday settings, ability to get in and out of the wheelchair and capacity to perform needed activities from the wheelchair.

While a child's physical capabilities clearly are important factors to consider, it is also essential that the wheelchair fits into the child's environment and the family's lifestyle. For example, the places where it will be used must be architecturally accessible. If the child cannot get into the bathroom at home using a particular wheelchair, that chair may not be a practical choice. Transportation considerations also are important. Is a van available to transport the individual in the chair, or does the chair need to fold so that it can be carried in the trunk?

The purchase price of a powered wheelchair rarely is less than $3,500; for the more deluxe models or those with specialized adaptations, the price can exceed $12,000. Like any major financial decision, purchase of a powered wheelchair should be undertaken with the utmost care to ensure that the product meets the needs of the user. For more information on selecting a powered chair, see "Powered Mobility for Your Child?" on page 33.

THE GROWING FAVORITE IN KIDS' POWER CHAIRS.



Unlike clothes, shoes, toys and some parents, the Zippie P500 can survive from childhood through adolescence unscathed.

That's because the Zippie P500 actually grows with kids, thanks to its wide range of adjustments and the innovative Zippie Growth Kit. Powered by a Direct Drive Motor System for maximum efficiency, the Zippie P500 lets kids get out there. Its programmable controller adjusts to meet their abilities. It even has a downsized power base, a kid-sized seating unit and 13 hot color options sure to please even the most cool-conscious youngster.

The Zippie P500 from Quickie...a chair kids and parents can agree on.

Terry Spees
Foster Parent &
Registered Nurse

"The Zippie P500 is incredibly maneuverable And Audrea loves the sleek design."

QUICKIE
The RealChair People.

QUICKIE
a division of SUNRISE MEDICAL

Quickie Designs Inc.
2842 Business Park Ave
Fresno, CA 93727-1328
(209) 292-2171
(800) 456-8168

Circle #93

© 1993 Sunrise Medical Quickie Designs Inc.

Three-year-old Jeanna Rait Kazmuski enjoys her new Regal Pediatric Scooter, manufactured by Bruno Independant Living Aids, Oconomowoc, WI.

Scooters

An alternative to either manual or powered wheelchairs is a scooter, or three-wheeled cart. A scooter looks and operates much like a golf cart. The user sits in a chair seat that usually is contoured to fit the body and may include a special seating cushion. The scooter is propelled through use of a steering mechanism located in front of the user, similar to riding a bicycle. Scooters provide power at a lower cost than many regular four-wheeled powered wheelchairs. Scooters also are thinner than many wheelchairs, making them more maneuverable.

Resources on Wheelchair Selection

The resources listed in this section focus primarily on adult wheelchair users. However, some of the information provided is applicable to the selection of wheelchairs for children.

How to Select and Use Manual Wheelchairs, A. Bennett Wilson, Rehabilitation Press, 1993. Available from: Rehabilitation Press, P.O. Box 380, Topping, VA 23169. Price: $12.50

- This guide helps new wheelchair users select a wheelchair with the right dimensions and seating system depending upon the degree of disability, goals of the user, and the environment in which the chair will be used. It also provides information about proper use and maintenance of wheelchairs.

Wheelchairs: A Prescription Guide, A. Bennett Wilson and Samuel R. McFarland, Rehabilitation Press, 1986. Available from: Rehabilitation Press, P.O. Box 380, Topping, VA 23169. Price: $14.95

- This small, straightforward publication addresses the factors to be considered by wheelchair prescribers. It is filled with illustrations and practical suggestions for making prescription decisions. Though intended primarily for prescribers, the information in this guide would be of value to an individual selecting a wheelchair for personal use. The information about manufacturers and product availability is slightly dated, but the basic concepts presented remain useful.

Choosing a Wheelchair System, Department of Veterans Affairs, 1990. Available from: Department of Veterans Affairs, Veterans Health Services and Research Administration, Washington, DC 20420. Price: FREE (Ask for the Clinical Supplement #2, Journal of Rehabilitation Research and Development, March 1990.)

- This resource was written by people with disabilities who have selected wheelchairs for many years, health care providers who prescribe wheelchairs, and researchers/engineers who participate in the development of new wheelchair designs.

Manual Mobility: Finding the Right Wheels, RESNA Videos. Available from: RESNA Third-Party Payer Program, 1700 N. Moore Street, Suite 1540, Arlington, VA 22209, (703) 524-6686. Price: $60.00 plus $5.00 shipping.

- This 30-minute video discusses the options to be considered for someone purchasing a manual wheelchair.

ABLEDATA Fact Sheets, Available from: ABLEDATA, (800) 227-0216 or (301) 588-9284; both numbers are for voice and TDD. Price: Single copies are FREE.

- Relevant ABLEDATA fact sheets include: *Funding Assistive Technology, Manual Wheelchairs, Powered Wheelchairs, Sports Wheelchairs, and Wheelchairs for Children.*

Wheelchair Standards

The American National Standards Institute (ANSI) recently approved a complete set of standards for wheelchairs. These standards consist of standard methods for measuring wheelchair components, and standard methods to test such things as a chair's strength, stability and turning radius.

The complete set of 18 standards is available from RESNA. These are very technical documents, probably of interest only to manufacturers and others who are going to conduct testing themselves. However, therapists and lay people may contact RESNA to request free summary documents that describe the standards in less technical language.

Invacare, one of the largest wheelchair manufacturers in the country, recently began advertising that its wheelchairs had been tested according to these standards. As consumers and therapists begin to ask for this information, it is expected that other manufacturers also will begin using the standards for testing—and advertising this fact to the public. Once this information becomes more readily available, it can be used by consumers and prescribers to make more informed purchasing decisions.

Wheelchair Standards are available from: RESNA, 1700 N. Moore Street, Suite 1540, Arlington, VA 22209, (703) 524-6686. Price: $180 for the complete set of 18 standards; $15 for individual standards. ■

This article was adapted from information contained in ABLEDATA fact sheets written by Lynn Bryant, ABLEDATA Project Director. Individual fact sheets are available free from ABLEDATA, a database of more than 19,000 products for people with disabilities. Call (800) 227-0216 or (301) 588-9284. Fact sheets may also be downloaded 24 hours a day from the free ABLEDATA electronic bulletin board system (301-589-3563, 1200–9600 baud, N-8-1). Included in the ABLEDATA database are descriptions of all types of wheelchairs currently available in the United States, as well as information about wheelchair manufacturers and local distributors. Information specialists are on hand to assist callers locate the information they need. For a small fee, ABLEDATA can provide patrons with computer printouts of information on specific wheelchairs listed in the database. Costs are determined by the size of the database search requested. Searches of 20 products or less are free; the charge is $5 per hundred products thereafter.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

MYDESC™
The Custom Desktop

1-800-4-MYDESC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2240 • MYDESC is a trademark of Rhamdec, Inc.

- Attendees may register for one, part of each, or both conferences and earn up to 50 credit hours Category I from the American Medical Association.
- A distinguished pediatric faculty will present materials in sessions, workshops, and roundtable discussions.
- The conferences will focus on timely pediatric subjects as well as healthcare reforms.
- Tuition is based on number of days in attendance.

FOR MORE INFORMATION, CALL HACKENSACK MEDICAL CENTER'S DEPARTMENT OF PEDIATRICS AT (201) 996-2371.

World Cup USA 94

Hackensack Medical Center
30 Prospect Avenue, Hackensack, New Jersey 07601
Affiliated with the University of Medicine & Dentistry of New Jersey and a member of the University Health System of New Jersey

We're with you for life!

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle #86

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
(609) 346-3300 • FAX (609) 435-4223
Brochure or video available upon request.

Circle #85

"Accreditation with Commendation"
Joint Commission on Accreditation of Hospital Organizations
Member: National Association of Children's Hospitals and Related Institutions

Powered Mobility for Your Child?

by Linda Petty

The suggestion to look into powered mobility may come from a therapist, a seating clinic or another parent—whatever the source, few parents welcome the recommendation with relief or enthusiasm. If your child has been focusing on therapy to develop skills for walking, considering an electric wheelchair—or "powered chair"—may seem akin to acceptance of permanent disability. You may feel like you are "giving in" or admitting failure. The suggestion may also come at the critical time of entry to school when changes in therapy supports and anxiety about school placement and success are prominent. Fears of injury to the child or to other children are quite reasonable! A rash of questions arise as families consider powered mobility: *How old does my child have to be to consider powered mobility? How will my child benefit from a powered chair? What kind of skills does he or she need before trying powered mobility? How much will it cost?*

199

Research Changes Opinions

Historically, powered mobility was reserved for adults. Even then, it was considered only as a last resort. Powered chairs were first made available to children with muscular dystrophy who were no longer able to propel a manual chair, or to older children who required rehabilitation following injuries. Professionals believed that if young children were given powered chairs, they would lose, or fail to develop the skills needed to walk. Professionals and parents also feared that children given powered chairs would be less motivated to participate in therapy programs aimed at developing muscle strength and coordination for walking, or that they would injure themselves—or peers that might get in their way—while learning to drive powered chairs.

Research in the past decade has shown that children as young as 24 months—an age by which able-bodied children are developing independent mobility skills—are able to safely operate powered mobility devices. Gaining independent movement through powered mobility also has been shown to have a positive impact on many aspects of a child's development. Children improve spatial orientation, increase independence and demonstrate better social skills for getting along with peers, with no negative effects on motor development. Adults and other children acquire a new respect for the abilities of these children after seeing their initiative and problem-solving skills.

Based on this research, powered mobility is increasingly being made available to very young children. Professionals now believe that the use of powered mobility reduces the risk of further developmental and social delays by providing varied and appropriate experiences for children in their homes, schools and communities.

Technological Advances

The development of new technology has also contributed to the increasing use of powered mobility by young children. In the past, powered chairs were available only with standard proportional joysticks and child-sized sling seats on adult chair bases. Manufacturers now produce child-sized, user-friendly chairs with a variety of standard and alternate controls. Microcomputer controls that allow the use of alternate controls have also been commercially available for the last few years.

These technological advances also have benefited older children with poor muscle control who were previously hard to fit with powered mobility. A variety of new features can compensate for deficits in physical control.

Look into powered mobility if:

❑ *The child has a need for independent mobility:* For children who are at a normal or near normal level of intellectual development, the need for independent mobility may occur as early as one-and-a-half to two years of age, just as it would in their peers. Independent mobility allows a child to play, explore the environment, and participate in school or family activities. Sometimes, a child who shows frustration or misbehavior as a result of his or her lack of mobility may be demonstrating his or her readiness for powered mobility.

Fun with a purpose: *Seven-year-old David controls a toy with a switch. This "fun" activity is preparing him to manipulate the controls of his new powered wheelchair.*

❑ *The child displays the skills that are required for powered mobility:*

- understands the concept of cause and effect,
- understands one step commands, and
- has adequate visual skills to perceive child-sized objects within a 10-foot radius.

Pre-driving skills can be developed by playing with switch toys, joystick- or switch-activated computer games, and participating in interactive games with peers.

❑ *The child has at least one reliable movement for activating a switch that could be used to operate powered chair controls:* The movement must be one that the child can repeatedly stop and start at will. It should also be a movement that the child can perform in a seated position. Many children can control a joystick, but powered chairs can also be driven with a variety of controls, so limited hand or arm control does not rule out powered mobility.

It is important to make the decision about switch location in consultation with your child's therapist. You will want to choose a switch site that will not have a negative effect on the way a joint or muscle works, or use reflex movements that the therapist is trying to minimize.

❑ *Family members are willing to accept powered mobility and supervise the child:* Supervision of the young child with a powered chair is just as necessary as supervision of a child on a bicycle. Supervision prevents accidents and keeps the child from venturing into unsafe environments. Learning to drive a powered chair is like learning any other physical activity or sport; a child won't perform well without regular supervised practice.

❑ *The child has an accessible environment in which to use the powered chair:* Many homes are not wheelchair accessible, but this should not preclude consideration of powered mobility. Using a powered chair for independent

200

Wheelchair trials: *Seven-year-old David tests out a powered wheelchair, while vision resource teacher Lenore Leonard (left), and seating equipment coordinator Stefanie Laurence (center) look on.*

mobility at school may be valuable for the child's social development and participation. A child also may be able to use a powered chair outdoors—in the yard and neighborhood—while storing and charging the battery in the garage.

- ❑ *A means of transportation for the powered chair is available:* This might be public transit, the family van or a school bus.
- ❑ *A manual wheelchair is not appropriate for the child:* This might be because the child cannot propel a manual wheelchair in an energy-efficient manner and cover required distances in acceptable time. A manual wheelchair would also be inappropriate if abnormal movement patterns are used to propel it.

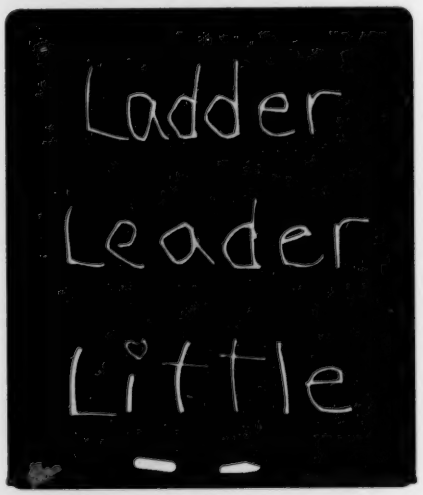
Other considerations

There will be other factors to think about as you consider powered mobility. It is important to obtain an assessment to determine the optimal seating and control method for a powered chair. This is especially important if the child has limited physical control. Many children also benefit from training in powered chair driving before prescription. A training program allows children to develop necessary skills and find the best driving method. See if your treatment center can offer such a program.

You must also plan for maintenance of the batteries and chair after purchase. Just like periodic automobile maintenance, this adds to the overall cost of the chair.

Weigh all these factors as you consider powered mobility for your child. Discuss them with therapists who are familiar with your child's physical, intellectual and social skills. Consider what independent mobility with a powered chair has to offer your child. Even if a powered chair is just an interim measure while walking skills develop—or just used for long distances, playgrounds and shopping—the potential benefits are worth consideration and exploration! ■

Linda Petty is an occupational therapist in the Communication and Assistive Technology Department at Bloorview Children's Hospital in Toronto, Canada. For the last 10 years, she has worked in clinics providing assessment, training and prescription of technical aids—including powered mobility controls—for children and young adults. Linda lives with her husband, Mark, in a 115-year-old family home outside Toronto. When not working or renovating the house, she enjoys gardening, windsurfing, making pottery and playing the piano.



IT'S A SHAME THEY DON'T HEAR WHAT THEY SEE

For every child striving to learn, a "little" can mean a lot. But for 1 in every 6 students, it doesn't mean that at all. Call today to find out why.

Can you afford to not hear what we have to say?
800-227-0735 U.S. / 800-263-8700 Canada

Phonic Ear
Circle #60

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

Circle #12

COLUMBIA

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle #26

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Circle #162

Operated by: **CRI**
B.R. (Bill) Walker, Ph.D.
Executive Director

Directory of Wheelchair Manufacturers

The types of wheelchairs manufactured by each listed company are designated by letter code: M=manual, P=powered, C=children's. Most companies manufacture young adult and adult manual wheelchairs. This list was provided by ABLEDATA, an assistive technology and adaptive communications database. For more information call ABLEDATA, (800) 227-0216.

21st Century Scientific
4915 Industrial Way
Coeur d'Alene, ID 83814
(208) 667-8800 (M, P)

Accumec
32 Race St
San Jose, CA 95126
(408) 294-3100 (M, P)

Action Technology
39350 Taylor Pkwy
North Ridgeville, OH 44039
(800) 424-4214 (M, P, C)

Alpha Mobility
PO Box 22137
Sarasota, FL 34276
(800) 749-5444 (P)

Amigo Mobility International
6693 Dixie Hwy
Bridgeport, MI 48722-0402
(800) 821-2710 (P)

Atlantic Rehabilitation
81 Rumford Ave
Waltham, MA 02254
(617) 894-0069 (M, P, C)

Australian Transcender Industries P/L
GPO Box 3908
Sydney 2001 NSW
Australia (P)

Bencraft
The Ave, Rubery, Rednal
Birmingham
England B45 9AP
021 457 9001 (M)

Biolink Computer R & D
4770 Glenwood Ave
North Vancouver, BC
Canada V7R 4G8
(604) 984-4099 (P)

Braun
1014 South Monticello
PO Box 310
Winamac, IN 46996
(800) 843-5438 (P)
See our ad on pg 27.

Bruno Independent Living Aids
1780 Executive Dr, PO Box 84
Oconomowoc, WI 53066
(800) 882-8183 (P,C)
See our ad on pg 25.

Burke Mobility Products
PO Box 1064
Mission, KS 66222
(800) 255-4147 (P)

C F Struck
W51 N545 Struck Ln, Box 307
Cedarburg, WI 53012
(414) 377-3300 (P)

California Cruisers
21742 Marilla St
Chatsworth, CA 91311
(818) 718-2828 (M)

Canadian Wheelchair Mfg
1360 Blundell Rd
Mississauga, Ontario
Canada L4Y 1M5
(416) 275-3960 (M, C)

Car Chair
Car Chair House, Station Rd
Industrial Estate
Hailsham, Sussex BN27 2ES
England (M)

Chair Concern
13150 Paramount Blvd
South Gate, CA 90280
(213) 630-4220 (P)

Colours 'N Motion
1591 S Sinclair St, Ste A
Anaheim, CA 92806
(800) 892-8998 (M)

Convaid Products
3541 A Lomita Blvd
Torrance, CA 90505
(800) 552-1020 (M)
See our ad on pg 20.

R J Cooper & Associates
24843 Del Prado, Ste 283
Dana Point, CA 92629
(800) 752-6637 (P, C)

Crown Medical
PO Box 132
Reynoldsburg, OH 43068
(614) 866-9803 (M)

Damaco/Freedom on Wheels
20542 Plummer St
Chatsworth, CA 91311
(800) 432-2434 (M, P, C)

DU-IT Control Systems Group
8765 Township Rd, #513
Shreve, OH 44676-9421
(216) 567-2906 (P)

Dufco Electronics
2847 N Business Park Ave
Fresno, CA 93727-1328
(800) 456-8168 (P)

Dupree Wheelchair Services
Rt 35, Box 335A
Gainesville, FL 32608
(904) 495-9459 (M)

Eagle Sportschairs
2351 Parkwood Rd
Snellville, GA 30278
(404) 972-0763 (M)

Electric Mobility
1 Mobility Plaza
Sewell, NJ 08080
(800) 662-4548 (P)

Elite Wheelchair Products
2884 Melissa Crt
Snellville, GA 30278
(800) 824-7903 (M)

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681 (C)

Eric's House
12503 44th Drive SE
Everett, WA 98203-9000 (P)

ETAC USA
2325 Parklawn Dr, Ste P
Waukesha, WI 53186
(800) 678-3822 (M, C)

Everest and Jennings
1100 Corporate Square Dr
St Louis, MO 63132-2908
(800) 235-4661 (M, P, C)

Everest & Jennings Canada
111 Snidercroft Rd
Concord, Ontario
Canada L4K 2J8
(415) 669-2381 (M, P, C)

Excel Mobility Products
636 Constitution Ave NE
Washington, DC 20002
(202) 544-0323 (P)

Falcon Rehabilitation Products
4404 East 60th Ave
Commerce City, CO 80022
(303) 287-6808 (M, P)

Folio Products
1341 Sherman Dr, Unit A
Longmont, CO 80501
(800) 356-4125 (P)

Fortress
827 Jefferson, PO Box 489
Clovis, CA 93612
(800) 869-4335 (M, P, C)

Gendron
400 E Lugbill Rd
PO Box 197
Archbold, OH 43502
(800) 537-2521 (M, P, C)

Golden Technologies
159 Penn Ave
Exeter, PA 18643
(800) 624-6374 (P)

Grove Innovations
120 W Church St
Centre Hall, PA 16828
(814) 364-2677 (M)

Guardian Products
4175 Guardian St
Simi Valley, CA 93063
(800) 255-5022 (M)

Gunnell
8440 State St
Millington, MI 48746
(800) 551-0055 (M, C)

Hadco Marketing Services
6601 NW 14th St, #2
Ft Lauderdale, FL 33313-4579 (P)

Halls Wheels
PO Box 380784
Cambridge, MA 02238
(617) 628-7955 (M)

Hausted
927 Lake Rd, PO Box 710
Medina, OH 44256
(800) 428-7833 (M)

Hoveround
1748 Independence Blvd, Ste B1
Sarasota, FL 34234
(800) 964-6837 (P)

IDC
Chatuzange le Goubet
26300 Bourg de Peage
France (M)

Imex Healthcare
1671 Dell Ave, Ste 202
Campbell, CA 95008-6903
(408) 370-6361 (M)

Interior Mediquip
PO Box 1875
Vernon, BC
Canada V1T 8Z7
(604) 542-1363 (M)

Invacare
PO Box 4028
899 Cleveland St
Elyria, OH 44036-2125
(800) 333-6900 (M, P, C)

Iron Horse Productions
2624 Conner St
Port Huron, MI 48060
(313) 987-6700 (M)

Jaken Medical—New Horizons
2310 East Orangethorpe Ave
Anaheim, CA 92806
(800) 678-4499 (M)

Kareco International
299 Rt 22 E
Green Brook, NJ 08812
(800) 852-7326 (M)

Kempf
1080 E Duane Ave, Ste E
Sunnyvale, CA 94086
(408) 773-0219 (P)

Directory of Wheelchair Manufacturers

Kendall-Futuro
5405 Dupont Cir, Ste A
Cincinnati, OH 45150-2735
(513) 576-8000 (M, C)

Kid-Kart
126 Rosebud, Ste #1
Belgrade, MT 59714
(800) 388-5278 (M, C)
See our ad on pg 26.

Kuschall of America
708 Via Alondra
Camarillo, CA 93012-8713
(800) 654-4768 (M)

Labac Systems
8955 S Ridgeline Blvd, Ste A
Highlands Ranch, CO 80126
(800) 445-4402 (P)

Leisure Lift
1800 Merriam Ln
Kansas City, KS 66106
(800) 255-0285 (P)

Lumex
100 Spence St
Bay Shore, NY 11706-2290
(800) 645-5272 (M)

Hugh Macmillan Rehabilitation Centre
350 Rumsey Rd
Toronto, Ontario
Canada M4G 1R8
(800) 363-2440 (P)

Medical Lab Automation
8110 Ulmerton Rd
Largo, FL 34641
(800) 237-1162 (M)

Medical Resource Companies of America
10670 N Central Expressway
Dallas, TX 75231
(800) 583-6565 (P)

Meyra/Five Star Mobility

Mobility Manufacturing
5555 S Country Club Rd
Tucson, AZ 85706
(800) 767-2668 (P)

Morgan Technology
2230 Wisconsin Ave
Downers Grove, IL 60515
(800) 906-5483 (M)

Motovator
1732 Border Ave
Torrance, CA 90501-3601
(310) 320-5941 (P)

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93060
(805) 525-7165 (M, C)

Omni Manufacturing
4355 International Blvd
Norcross, GA 30093
(800) 554-9215 (M)

Orthofab
500 Rue Desrochers
Ville Vanier, Quebec
Canada G1M 1C2
(418) 681-0667 (P)

Ortho-Kinetics
W220 N507 Springdale Rd
PO Box 1647
Waukesha, WI 53187-1647
(800) 588-7786 (M, P)

Otto Bock
3000 Xenium Ln N
Minneapolis, MN 55441
(800) 328-4058 (M)

Patient's Personal Needs
275 Centre St
Holbrook, MA 02343
(800) 289-4776 (M)

Peachtree Medical Systems
5002 N Royal Atlanta Dr, Ste P
Tucker, GA 30084
(404) 939-1122 (P)

Peachtree Patient Center
3123 Presidential Dr
Atlanta, GA 30340
(404) 457-0700 (P)

Permobil of America
6 B Gill St
Woburn, MA 01801-1721
(800) 736-0925 (P)

Pin Dot Products
6001 Gross Point Rd
Niles, IL 60648-4027
(800) 451-3553 (M)

Poirier S.A.
Usine des Roches-Fondettes
37230 Luynes
FRANCE (M, C)

JA Preston
PO Box 89
Jackson, MI 49204
(800) 631-7277 (M, C)
See our ad on the back cover.

Pride Health Care
71 S Main St
Pittston, PA 18640
(800) 457-5438 (P)

Quest Technologies
766 Palomar Ave
Sunnyvale, CA 94086-9716
(408) 739-3550 (P)

Quickie Designs
2842 Business Park
Fresno, CA 93727
(800) 456-8168 (M, P, C)
See our ads on pgs 17 & 29.

Quickie Designs/Shadow Products
20604 84th Ave S
Kent, WA 98032-1224
(800) 342-1579 (M)

Ranger All Season
PO Box 132
George, IA 51237
(800) 225-3811 (P)

Redman Wheelchairs
945 E Ohio St #4
Tucson, AZ 85714-1694
(800) 727-6684 (M, P, C)

Rehab Centre for Children
633 Wellington Cres
Winnipeg, Manitoba
Canada R3M 0A8
(204) 452-4311 (M, C)

Rehabco
1513 Olmstead Ave
Bronx, NY 14202
(718) 829-3800 (M, P, C)

RETEC USA
10 Centre Dr
Orchard Park, NY 14127
(800) 877-3832 (P)

RolControl Products
6750 Worth Way
Camarillo, CA 93012
(805) 386-4191 (P)

Rx Rocker
3541 Old Conejo Rd, #101
Newbury Park, CA 91320
(800) 762-5371 (M)

Samhall Rehab
300 Long Beach Blvd
Stratford, CT 06497-7153
(800) 882-0098 (M, C)

Seidel Electronics
466 W Market St
Akron, OH 44303
(216) 376-3817 (P)

Steven Motor Chair
120 N Gunter
Siloam Springs, AR 72761
(501) 524-8448 (P)

Stroller-Pack
134 N Franklin St
Juneau, AK 99801
(800) 487-9652 (C)
See our ad on pg 46.

TM Innovative Products
830 South 48th St
Grand Forks, ND 58201
(701) 772-5185 (P)
See our ad on pg 43.

Tallahassee Therapeutic Equipment
9601 Miccosukee Rd, Lot 13
Tallahassee, FL 32308-9609
(800) 476-0487 (M)

Tarsys Engineering
101 Bartley Dr
Toronto, Ontario
Canada M4A 1C9
(415) 751-9992 (P)

Technovation
6373 W Glenbrook Rd
Brown Deer, WI 53223
(414) 354-8895 (M)

Tetra Development Society
Plaza of Nations, Box 27
770 Pacific Blvd S
Vancouver, BC
Canada V6B 5E7
(604) 688-6464 (P, C)

Theradyne
21730 Hanover Ave
Lakeville, MN 55044
(800) 328-4014 (M, P, C)

Top End by Action
4501 63rd Cir N
Pinellas Park, FL 34665
(800) 532-8677 (M)

Tuffcare
2700 Saturn St #A
Brea, CA 92621-6704
(800) 367-6160 (M)

Up and Over Engineering
1509 Liberty St
El Cerrito, CA 94530
(415) 233-1328 (M)

Valutec AG
Bleicheweg
CH-5605 Dottikon
Switzerland (M)

Voyager
68102 US Hwy 31
Lakeville, IN 46536-9738 (P)

Wheel Ring
199 Forest St
Manchester, CT 06040
(203) 647-8596 (M, C)

Wheelchair Institute of Kansas
PO Box 777
La Crosse, KS 67548
(800) 537-6454 (M)

Wheelchair Store
12025 Shiloh Rd, Ste 230
Dallas, TX 75228
(800) 648-1884 (P)

Wheelsport International
105 W Dakota, Ste 114
Clovis, CA 93612
(209) 276-3271 (M, C)

Whitmyer Biomechanix
848 Blountstown Hwy, Ste H
Tallahassee, FL 32304
(904) 575-5510 (M)

XL Wheelchairs
1020 Marauder St, Ste 102
Chico, CA 95926
(800) 356-3554 (M, C)

Zygo Industries
PO Box 1008
Portland, OR 97207-1008
(800) 234-6006 (P)

Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Associations with leading specialists and major medical centers

Affiliation with SUNY

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

Circle #6

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

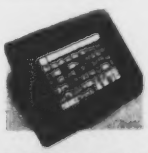
Circle #39

You Asked DynaVox To Do Even More...

"I want to spell and talk faster."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at **1-800-344-1778.**



We Hear You.

TECHNOLOGY INC.

Circle #68

REACH FOR THE STARS

ABILITIES EXPO '94

New Jersey & California

The #1 Show of Products and Services for People with Disabilities

Opportunities to try and buy on the Show floor

One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-Wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

Longest running show of its kind in the U.S.

Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO in a city near you:

ABILITIES EXPO EAST
Edison, NJ
Raritan Expo Center
April 15–17, 1994

ABILITIES EXPO WEST
Anaheim, CA
Anaheim Convention Center
May 20–22, 1994

For more information on attending please call 203/256-4700.

SAVE ONE DOLLAR • SAVE ONE DOLLAR

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. *Name and address must be completed to validate coupon.*

Name _____

Address _____

City _____ ***State*** _____ ***Zip*** _____

Telephone (____) _____ – _____ ***CA/NJ94 J***

ABILITIES EXPO — *New Jersey* — **Produced by Expocon Management Associates, Inc. and RCW Productions Inc.** — *California* — ABILITIES EXPO

Directory of Cushion Manufacturers

Accu-Back
1475 E Del Amo Blvd
Carson, CA 90746
(213) 639-7992

Action Products
22 N Mulberry St
Hagerstown, MD 21740
(800) 228-7763

Activeaid
1 Activeaid Rd
PO Box 359
Redwood Falls, MN 56283-0359
(800) 533-5330

Adamin
39 Haven Ave
Bergenfield, NJ 07621
(800) 833-3725

Alagold
1920 S Court St
PO Box 4959
Montgomery, AL 36103
(205) 834-6900

Alexander Industries
PO Box 4913
Akron, OH 44310
(800) 345-7341

Alimed
297 High St
Dedham, MA 02026
(800) 225-2610

Allyn Air Seat
18 Millstream Rd
Woodstock, NY 12498
(914) 679-2051

Alpha Protech
903 W Center St, Bldg E
N Salt Lake, UT 84054
(800) 527-7689

Anna Dote
Box 40, Pullam Dr
W Middlesex, PA 16159
(800) 346-6132

Back Ease
PO Box 5283
Louisville, KY 40205
(502) 451-0394

Backsaver Products
53 Jeffrey Ave
Holliston, MA 01746
(617) 429-5940

Bandy Aids
423 State St
Bowling Green, KY 42101-1240
(800) 326-5173

Bauerfeind USA
1590 N Roberts Rd, #J14
Kennesaw, GA 30144-3679
(800) 423-3405

Bell-Horn
451 N 3rd St
PO Box 3408
Philadelphia, PA 19123
(800) 523-4518

Better Sleep
57 Industrial Rd
Berkeley Heights, NJ 07922
(908) 464-2200

Biotech
PO Box 7036
Grayslake, IL 60030
(800) 526-2158

Bodycare
315 Gilmer Ferry Rd
Ball Ground, GA 30107
(800) 858-9888

Bodyline Comfort Systems
3730 Kori Rd
Jacksonville, FL 32257
(800) 874-7715

Canyon Products
10173 Croydon Way
Sacramento, CA 95827
(800) 221-5499

Cascade Designs
4000 1st Ave S
Seattle, WA 98134
(800) 527-1527

CHS International
PO Box 21067
550 39th Ave NE
Columbia Heights, MN 55421
(800) 878-4550

Comfort Cover
1676 Industrial Blvd
Chula Vista, CA 92011
(619) 423-2118

Comfort Med
609 Interchange Dr SW
Atlanta GA 30336-1603
(800) 527-3626

Comfy Back/Evans
1611 Lincoln Blvd
PO Box 988
Venice, CA 90294
(800) 272-6639

Commander Omni
PO Box 246
Garden City, NY 11530
(800) 645-4704

D A Schulman
7701 Newton Ave N
Brooklyn Park, MN 55444
(612) 561-2908

Danmar Products
221 Jackson Industrial Dr
Ann Arbor, MI 48103
(800) 783-1998

The following list of wheelchair cushion manufacturers was provided by ABLEDATA, an assistive technology and adaptive technology database. For more information call ABLEDATA, (800) 227-0216.

Dermacare
7651 National Turnpike
Louisville, KY 40214
(800) 626-4550

Duro Med Industries
301 Lodi St
Hackensack, NJ 07602
(800) 526-4753

Dynamic Systems
Rte 2, Box 182B
Leicester, NC 28748
(704) 683-3523

The Jay® GS Cushion and Back, Manufactured by Jay Medical, Boulder, CO.

Embracing Concepts
40 Humboldt St
Rochester, NY 14609
(800) 962-5542

Everest and Jennings
1100 Corporate Square Dr
St. Louis, MO 63132-2908
(800) 235-4661

Foam Products
4747 Bronx Blvd
Bronx, NY 10470
(800) 283-4362

Frank Stubbs Company
4518 Vanowen St
Burbank, CA 91505
(800) 223-1713

Fred Sammons
Box 32
Brookfield, IL 60513-0032
(800) 323-5547

Freedom Designs
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551

G E Miller
540 Nepperhan Ave
Yonkers, NY 10701
(800) 431-2924

Gaymar Industries
10 Centre Dr
Orchard Park, NY 14127
(800) 828-7341

Gendron
400 E Lugbill Rd
PO Box 197
Archbold, OH 43502
(800) 537-2521

Golden Fleece International
14240 60th St N
Clearwater, FL 34620
(800) 562-7326

Grandmar
1311 63rd St
Emeryville, CA 94608
(415) 428-0441

Grant AirMass
986 Bedford St
PO Box 3456
Stamford, CT 06905
(800) 243-5237

Hartwell Medical
6352 Corte Del Abeto #j
Carlsbad, CA 92009-1408
(800) 633-5900

Health and Medical Techniques/Aquatherm
PO Box 2697
Smithtown, NY 11787
(800) 526-4296

HealthFLEX
127 Bowen Rd
Bennington, VT 05201-2017
(800) 782-8889

Heelbo
5745 W Howard St
Niles, IL 60648
(800) 323-5444

Hermell Products
23 Britton Dr, Box 7345
Bloomfield, CT 06002
(800) 233-2342

Homedics
6841 N Rochester Rd, Bldg H
Rochester Hills, MI 48306
(800) 333-8282

JA Preston
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
See our ad on the back cover.

Directory of Cushion Manufacturers

JT Posey
5635 Peck Rd
Arcadia, CA 91006
(800) 423-4292

Jay Medical
PO Box 18656
Boulder, CO 80308-8656
(800) 648-8282
See our ad on pg 3.

Jefferson Industries
205 Nassau St
Princeton, NJ 08540
(800) 257-5145

Jobst Institute
PO Box 653
Toledo, OH 43694
(800) 537-1063

Kees Goebel Medical Specialties
9663 Glades Dr
Hamilton, OH 45011
(800) 354-0445

Ken McRight Supplies
7456 S Oswego
Tulsa, OK 74136
(918) 492-9657

Kendall-Futuro
1 Riverfront Pl, Ste 900
Newport, KY 41071
(800) 933-0210

Larkotex
1002 Olive St
PO Box 449
Texarkana, TX 75501
(800) 972-3037

Lotus Health Care Products
31 Sheridan Dr
Naugatuck, CT 06770
(203) 723-1494

Luba Medical Supplies
6187 NW 167th St, #H24
Miami, FL 33015
(305) 556-5559

Lumex
100 Spence St
Bay Shore, NY 11706-2290
(800) 645-5272

Luxury Liners
14747 Artesia Blvd, Bldg D
La Mirada, CA 90638
(800) 247-4203

Maddak
6 Industrial Rd
Pequannock, NJ 07440
(800) 443-4926

Mason Medical Products
8000 Cooper Ave, Bdlg 28
Glendale, NY 11385
(800) 233-4454

5 Models Available Now

BIGFOOT

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Circle #42 Photo used by permission Bigfoot 4 X 4 Inc. St. Louis, MO

Med Foam
5250 Klockner Dr
Richmond, VA 23231
(800) 343-8112

Medical Devices International
3849 Swanson Ct
Gurnee, IL 60031
(800) 323-9035

Medical Specialties
4911 Wimot Rd
Charlotte, NC 28208
(800) 334-4143

Medpro
275 Highway 18
East Brunswick, NJ 08816
(800) 257-5145

Mor Loc
PO Box 427
Conover, NC 28613
(800) 438-9201

Otto Bock
3000 Xenium Lane N
Minneapolis, MN 55441
(800) 328-4058

PA Medical
PO Box 1286
Columbia, TN 38401
(615) 381-3422

PCP Champion
300 Congress St
Ripley, OH 45167
(800) 888-0867

Pin Dot Products
6001 Gross Point Rd
Niles, IL 60648
(800) 451-3553

Posture Comfort Cushion
59-29 174th St
Fresh Meadows, NY 11365
(718) 631-1734

Profex Medical Products
PO Box 16043
St Louis, MO 63105
(800) 325-0196

Quickie Designs
2842 Business Park
Fresno, CA 93727
(800) 456-8168
See our ads on pgs 17 & 29.

Roho
PO Box 658
Belleville, IL 62222
(800) 356-2990

Roloke
5760 Hannum Ave
Culver City, CA 90230
(800) 533-8212

Scott Specialties
PO Box 129
Belleville, KS 66935
(800) 255-7136

Sheepskin Ranch
3309 Winthrop, Ste 85
Fort Worth, TX 76116
(800) 366-9950

Skil Care
167 Saw Mill River Rd
Yonkers, NY 10701
(800) 431-2972

Southwest Technologies
2018 Baltimore
Kansas City, MO 64108
(800) 247-9951

Span America
PO Box 5231
Greenville, SC 29606
(800) 888-6752

Special Health Systems Ltd.
225 Industrial Parkway S
Aurora, ON
Canada LAG 3V5
(800) 263-2223

Spenco Medical
6301 Imperial Dr
Waco, TX 76712
(800) 433-3334

Spinal Technologies
1985 Rutgers Univ Blvd
Lakewood, NJ 08540
(800) 257-5145

Stat Medical
200 Debusk Ln
Powell, TN 37849
(800) 251-9864

Steridyne
3725 Investment Ln
Riviera Beach, FL 33404
(800) 327-6185

Stryker
420 Alcott St
Kalamazoo, MI 49001
(800) 253-3210

Sween
1940 Commerce Dr
PO Box 8300
North Mankato, MN 56001
(800) 533-0464

Thompson Medical Specialties
4301 Bryant Ave S
Minneapolis, MN 55409
(800) 777-4949

Total Care
18910 Bonanza Way
Gaithersburg, MD 20879
(301) 840-9027

Winganna Care Products
1612 Highway 93
Polson, MT 59860
(406) 883-2337

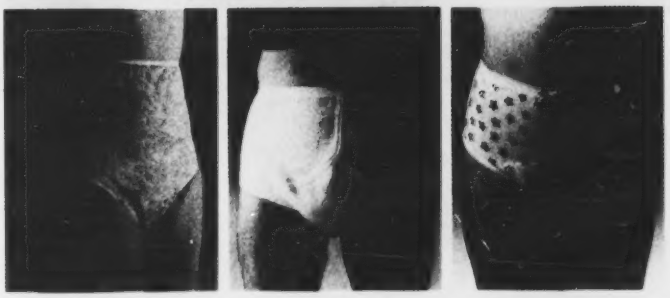
208

The Next Step In Dealing With Incontinence

If incontinence is part of your life, you're not alone.

For millions, it's a fact of life. But now there's a better way to deal with it.

Now there's Hypersorb,™ a new technology that brings a new level of comfort and confidence to incontinence products.



For women and men, girls and boys: Hypersorb looks like activewear, works like incontinence wear.

What's more, it's also reusable, so it brings a new level of economics. And that's not all.

As you can see, it has the fashion of activewear, so it will appeal to everyone from children to seniors.

We know it works; it's been working for years throughout Europe under the brand name Ganmill.

Even uncompressed, it's only 4mm thick, so it can be used in a variety of fashionable designs.

You'll also notice that there's a lot less bulk than you expect in an undergament that works so well.

And it keeps working a long, long time. After multiple washings, its absorbency is still 1000%. Which means it can save you quite a bit of money over disposables.

Even better, this also works for our environment. We use only pure polyester and viscose fibers; add no chemical binders or wood pulp products.

All told, we believe that Hypersorb will work better than whatever you're using now.

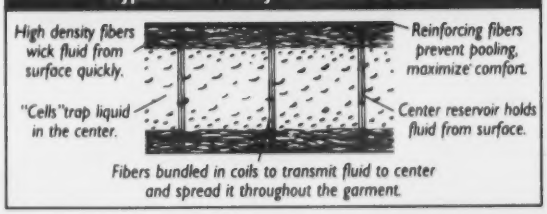
But talk is cheap. We back that up with a One-Year Guarantee. Follow instructions, and if Hypersorb doesn't keep working, send it back. We'll give you a new one or your money back.

So call, write or fax us. MasterCard, Visa and personal checks are accepted. Do it now.

Because you've got nothing to lose.

And you've got a much better way of dealing with incontinence to gain.

Hypersorb : Why It Works Better.


High density fibers wick fluid from surface quickly.
"Cells" trap liquid in the center.
Reinforcing fibers prevent pooling, maximize comfort.
Center reservoir holds fluid from surface.
Fibers bundled in coils to transmit fluid to center and spread it throughout the garment.

Ganmill
Personal Healthcare & Hygiene

HYPERSORB PATENT PENDING

TMI
TECHNOMARKETING INC

307 Bacon Road • Rougemont NC 27572 • (919) 477-1387 • Fax (919) 477-2294

Circle #122

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

Circle #18

LOST *in the* MALL!

A trip to the mall: *10-year-old Jerad Kratz with mom, Linda.*

by Linda Kratz

Why must everyone stare at my child in his electric wheelchair? It seemed that every time we went to the mall, a restaurant or any other public place, everyone stared at my son. But were they really staring? I would have sworn they were…until a Saturday afternoon at the mall changed my mind.

I had waited until the last possible day to buy season passes to the amusement park. I knew the line in the mall would be long; I'd be waiting for at least two hours. I told my husband that I would be back later, but he decided he wanted to go along and take the kids—Brad, a very active four-year-old and Jerad, our ten-year-old who drives an electric wheelchair.

I tried to dissuade him. I have been to the mall on a Saturday with both kids—it's a fate I would not wish on anyone! But Steve insisted. "It'll be fun," he told me, "I'll walk around the mall with the kids while you wait on line."

So, we headed for the mall. I went in and began my wait at the end of a very long line, while Steve and the kids headed into the crowds.

I had been in line for only a few minutes when Steve rushed up with Brad in tow. Thrusting our four-year-old at me he exclaimed, "You hold him for a few minutes. He just took off on me and I had to chase him. Hang onto him while I go get Jerad."

I knew that something like this would happen. I didn't get too excited until I started looking around the corner and didn't see Jerad coming. I'd assumed that Jerad was just a few feet behind. This was not the case.

The mall is about 2 blocks long. I was in a hallway near the middle. Steve had been at one end with both kids when Brad ran off. After catching him and handing him off to me, he went back to where he had left Jerad. You guessed it—Jerad was gone.

The woman just in front of me in line told me she would save my spot while I joined the search. Keeping a firm grip on Brad's hand, I ran down the mall toward the end where Jerad had been last seen. I looked in every store to see if I could spot him or evidence that he had been through there—toppled racks would've been a good clue. Every few feet, I stopped to ask passersby if they had seen a child driving an electric wheelchair. Nobody had seen him! Why—today, of all days—were people not staring?

Enjoying the great outdoors: *Jerad, four-year-old Brad and dad, Steve, go for a bike at Lost Maples State Park.*

My husband had notified mall security. While running down the mall, I heard loudspeakers blare, "We are looking for a lost child in an electric wheelchair. Please contact mall security if you see him."

"How in the world can you lose a child in a wheelchair?" I asked myself. "This could only happen to us."

It took me about 15 minutes to get from one end of the mall to the other. Just as I reached the far end of the mall, I spotted Steve and Jerad coming out of the last store.

Steve had found him in the store "just driving around" being a normal 10-year-old. Since Jerad is legally blind—he has peripheral vision only—this is not something that I would let him do on his own. Fortunately, the mall has only one set of stairs, and he didn't go down that hallway.

I was so excited to see Jerad that all the anger I had been feeling was overcome by my joy. Never in my wildest dreams had I ever imagined losing Jerad—Brad, yes; but never Jerad. I wasn't really worried that anyone would take him—the electric wheelchair alone weighs 250 pounds. I was more concerned about him being frightened or driving off the stairs. At the same time, I was proud that Jerad was independent enough to make it from one end of the mall to the other.

As it turned out, Jerad was not at all upset at being left alone. In fact, he liked it. Until this past year, Jerad had been easily frightened and very dependent on us. We had worked very hard to make him more confident and independent. Can we take some of his new-found daring back?

This experience taught me just how normal our children really are. It also taught me that people are not always staring. ■

Linda Kratz lives in San Antonio, Texas with her husband and two sons. She is a co-founder of the Parent Information Exchange, a non-profit organization for parents of children with disabilities. She is also a member of the Texas Assistive Technology Partnership Council. Her first article for Exceptional Parent, *"Electric Wheelchairs... Is it Giving Up or Giving?" appeared in October 1992.*

STROLL INTO A NEW WORLD

Not only can you take your child to places you both would like to go, our SPECIAL NEEDS STROLLER PACK will give your child a whole new outlook.

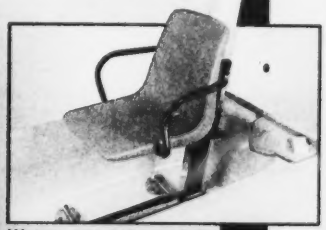
STROLLER Pack
A Way of Life

Circle #78
1-800-487-9652
SKAGGS & INGALLS INC.

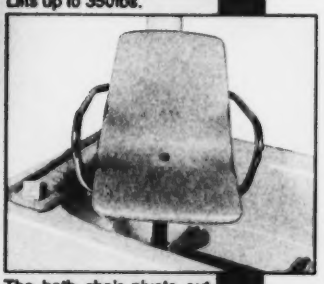
BATH-MATE ™
Water Powered Bath Lift

The Bath-Mate fits your existing tub without modifications

Circle #67



Water pressure alone supplies the lifting action. Lifts up to 350lbs.



Safe Bathing Promotes more Independence....

The Bath-Mate raises slowly to wheelchair height and lowers within 2 inches of tub bottom.

Optional:
- Seat Belts
- Arm Rest

The bath chair pivots outward for safe transfers.

(800)947-6565

P.O. Box 80095 Ontario, Ca. 91758

In Defense of My Daughter

by Judy Horton

Years ago we played with our fat baby and occasionally worried that the day would come when she would go out into the world, and the world would be cruel to her for no reason at all. That the day would come when the world would look upon the one we loved with all our hearts and see only the defect, the difference. Not her personality full of hope and alive with expectation, or her gentleness, or her terrific sense of humor or her precious little face with a beauty all its own. Just a syndrome named for Dr. Down.

"I'll be understanding," I said. "If some kid is mean, I'll explain to him about Kelly. It's really just a matter of education. Kids need to learn. They're afraid of what they don't understand."

"Yeah," said my husband. "Education. That's the thing to remember." And we looked at each other, and we looked at Kelly, and he muttered under his breath, "And then I'll rub the kid's nose off on the sidewalk." He took his fat baby girl and he hoisted her high in the air, and she laughed. He blew raspberries on her belly, and she gave forth her deep rolling chuckle.

Now that baby is eight years old, a person of fine sensibilities and definite opinions. Although we know she gets teased, we seldom see it.

But one day last year I saw it, on the playground of a church summer day care program for elementary school-aged kids. As we entered the yard one girl stage-whispered loudly to her two friends, "Look! There's that REE-tard. Ooooh, I hope she's not coming here!"

My eyes flew to Kelly's face where I saw a mask of stony indifference and icy dignity instantly install itself across her delicate features. And I knew that this was not the first time Kelly had experienced being summed up in the word "REE-tard."

The person in charge had heard this pronouncement too, but chose to pretend he had not. I politely pretended I had not heard it either. The little girls retreated to a corner of the playground, snickering and staring. There would be no room for Kelly at this particular inn. After many phone calls back and forth to discuss whether the center could meet her "needs," we ended up with no day care for the summer. (Her "needs" are these: She eats, plays, sleeps and loves to play with friends. She's a little poky and somewhat slow to catch on. She's seldom the only one.)

I hated myself for being tongue-tied. I hated Taylor, Texas. I hated the church. I hated that little girl. I hated her friends. I hated the day care worker and the director too.

We came home and Kelly went to her room to play with Heather, the imaginary friend who never fails her. My

Kelly Horton, age eight.

husband, Jerry, came home, and I cried and raged. I resolved I would never allow a thing like that to happen to my child again in my presence. I stormed to the word processor and wrote a script for myself entitled *In Defense of My Daughter*. I committed it to memory.

Yesterday, a year later, I recited it to a young boy at the town swimming pool. He was putting on a macho act for his little friends as Kelly played by herself in the water. He twisted his mouth around and hung his tongue out in a grotesque parody of our brothers and sisters and children who have mental retardation. (Kelly does not have tongue thrust, but never mind that.) He pulled his hands up and bent them over at awkward angles and lurched around with his head contorted against his neck. (Kelly has no trace of cerebral palsy, but never mind that either.) The little boys stared at Kelly and laughed at their friend's cleverness.

I strode confidently to the side of the pool and caught his eye. "Come over here," I said. He glanced around nervously, hoping I was talking to someone else. "You!" I said loudly—Ursula the Sea Witch appears at Taylor Pool! He approached the rim of the pool. I did not crouch down in a friendly manner. I drew myself up even taller.

"You are making fun of my little girl," I said.

"No ma'am," he said. "I wasn't, no, really."

"You were too," I said, "and I want you to stop it. My daughter has Down syndrome. That's the way she was born. God made her just as he made you. That's the way he made her, and he does not make mistakes. He is ashamed of you for the way you are acting, and I am ashamed of you, and you should be ashamed of yourself."

"Yes, ma'am," he said to the Sea Witch whose voice had risen and now drew the attention of a major portion of the kiddie pool. His eyes were huge and full of fear, all bravado long since gone. I waited for the words to sink in.

"Please tell me you will never do that again," I said, committing him to a lifetime of disability awareness and inclusive behavior.

"Yes, ma'am," he said. "I mean, no ma'am, I won't."

"Thank you," I said. "She is my daughter, and I love her just like your own mom loves you. I won't let anyone hurt her feelings, just like your mom won't let anyone hurt you"—I hoped this was true.

"Yes, ma'am," he repeated, tentatively backing away. He may have been uncertain of God's intentions in this matter, but made no mistake about mine.

He was thus demoted from tormentor to just another tow-headed eight-year-old with big blue eyes. Likewise, I hoped that Ursula the Sea Witch had become just some kid's mom as I returned to my bench.

Kelly had watched this exchange from a corner silently, a little alarmed that perhaps she had done something wrong. She stood transfixed in the water as the offender returned to his friends and began a game of chase.

Then, she looked up at me and smiled. "Look at me, Mommy," she said. "I stand on my hands." She dived down and stood on her hands, then surfaced, happily proclaiming, "I am a fish."

And my heart was sad, and my heart was happy. ■

Top: Kelly, 15 months.
Bottom: Kelly and Dad.

Judy Horton lives in Elgin, Texas, where she and her husband, Jerry, are developing a Christian community for people with mental retardation. Kelly, born in 1984, has Down syndrome. She is a valued member of a regular class in her local school.

Laureate

TALKING SOFTWARE FOR SPECIAL NEEDS

Free Book!

Laureate's book, *Sequential Software for Language Intervention*, describes seven stages of language development from birth to adulthood. Learn how our talking software can improve your child's communication skills.

Call for a FREE BOOK and our new 1994 catalog.
1-800-562-6801

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Circle #48

Crystal Springs School

A PROGRAM OF THE
INSTITUTE FOR DEVELOPMENTAL DISABILTIES, INC.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availability.
- Licensed by the Massachusetts Office for Children.
- Approved by the Massachusetts Department of Education.
- Member of the Massachusetts Association of Approved Private Schools.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537

Circle #151

Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Colleta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills, personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

In A World Where Love Is Sometimes In Short Supply

We Have It In Abundance

NINETY YEARS

St. Coletta School

W4955 Highway 18
Jefferson, Wisconsin 53549

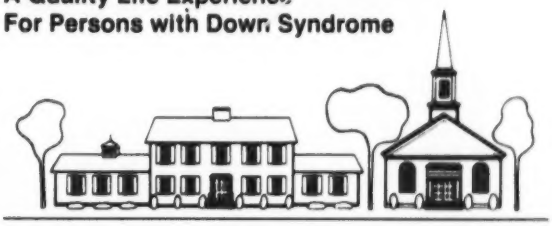
Circle #74

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.

Pathfinder Village

A Quality Life Experience For Persons with Down Syndrome



In this picturesque colonial village, located in scenic central New York State, life is full of wholesome activities and rewarding opportunities. Residents with Down Syndrome experience the joy and personal satisfaction of learning, working, and participating in a vital, dynamic community. Our year-round, co-ed program includes education, recreation, and employment opportunities plus the chance to live life to the fullest. *Call us today.*

R.R. #1, Box 32-A, Edmeston, NY 13335
Telephone (607) 965-8377

Circle #161

PI BEAR™ (Physically Inconvenienced)

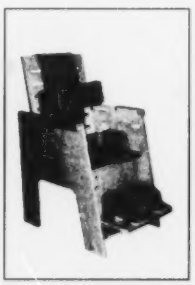
A Beary Special Friend

PI BEAR is a special friend that children can call their own. PI's three illustrated storybooks, which tell about his accident, recuperation, first day of school and other adventures with friends, can help disabled children understand their own feelings of fear and uncertainty. PI's friends also show others that your friends are friends, no matter what. PI BEAR and his wheelchair are approximately 14" tall. Dressed in a PI BEAR T-shirt, he comes with three story books (in chair backpack), a club membership certificate and a one-year warranty.

For more information, call: 1-800-467BEAR (2327)
Canada inquiries call: 613-258-0177.
VISA/MASTERCARD accepted.
Flexpay Available.

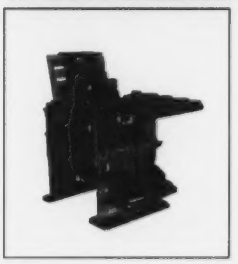
© 1993 PI BEAR CO. Patent pending

Circle #123



My name is Jed, but they call me *"Chairman of the Board".*

That's because my dad builds all kinds of equipment just for me. Call him for a catalog and an inservice demonstration.



- Products are fully adjustable. Excellent for child evaluations.
- Unique designs which serve the child, parents & professionals.

SPECIAL DESIGNS, inc

CUSTOM EQUIPMENT FOR SPECIAL KIDS

(908)-464-8825

Circle #71

P.O. Box 130, Gillette, NJ 07933

CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

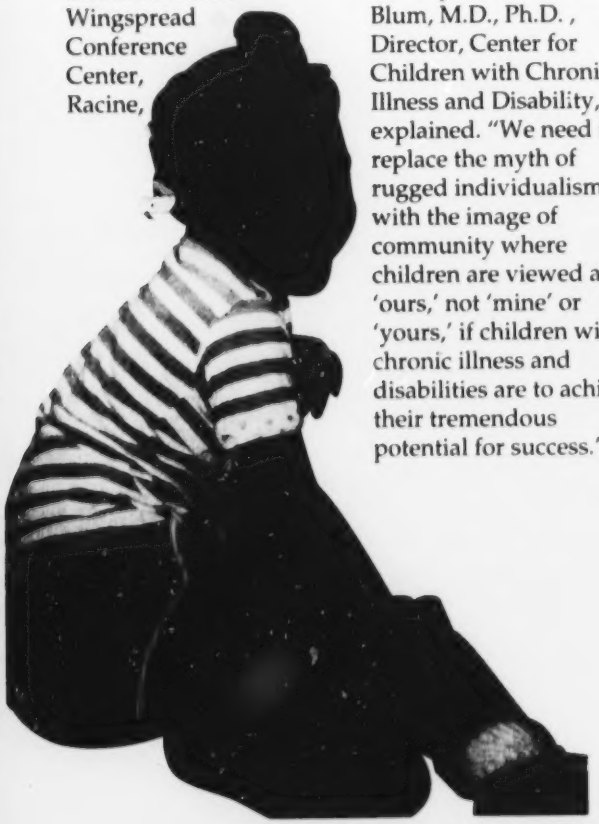
INSIDE

Health Policy & Chronic Illness:

Collaborating to Influence the Health of Children

This may be the time to challenge some of the fundamental assumptions that underlie policy and program decisions for children and youth with disabilities.

That's why more than 40 physicians and other health care providers, researchers, parents, educators and policymakers participated in last spring's special working conference at the Wingspread Conference Center, Racine, Wisconsin, "Reclaiming the Health of Children: Towards a New Model of Child and Youth Health Services."



"There needs to be a fundamental change in our thinking in this country," Robert Wm. Blum, M.D., Ph.D. , Director, Center for Children with Chronic Illness and Disability, explained. "We need to replace the myth of rugged individualism with the image of community where children are viewed as 'ours,' not 'mine' or 'yours,' if children with chronic illness and disabilities are to achieve their tremendous potential for success."

To insure a healthy future for children, our current public and private service systems must become more comprehensive and integrated. Policies must capitalize on collaboration among education, health, social and economic support services."

In one weekend, participants turned out five overarching recommendations in the areas of systems change. These recommendations were then presented at three meetings, one in Washington, DC, San Francisco and Minneapolis. These discussions brought together health care and education professionals, parents, researchers, and policymakers (who are national leaders) with the task of turning the recommendations into action and implementation plans.

"These meetings generated more than we had ever hoped," Blum says. "Specifically, we were able to revise the recommendations, generate a very substantial scope of work and evolve a core set of next steps that we at the Center will be undertaking."

The Center is working in close collaboration with other groups in five priority areas:

Health Policy & Chronic Illness
Turn to page 54

Children's Health Notes

MANAGING EDITOR
Peggy Mann Rinehart

PRODUCTION/
EDITORIAL ASSISTANT
Linda Pratt

STAFF:
Center for Children with Chronic Illness and Disability
Robert Wm. Blum, M.D., Ph.D., Director; Joan Patterson, Ph.D., Director of Research; Peter Blasco, M.D., Director of Education; Harriet Kohen, M.A., Center Coordinator; Pat Faulkner, Field Coordinator; Peggy Mann Rinehart, Director of Communications; Nancy Okinow, M.S.W., Parent & Policy Coordinator; Karen Stutelberg, Administrator; Clara Wolman, Ph.D., Research Coordinator; Sandra Kothe, Center Secretary.

This issue of ***Children's Health Notes*** *has been prepared for publication in* Exceptional Parent. ***Children's Health Notes*** *is published periodically and is made possible through Grant H133B90012 from the National Institute on Disability and Rehabilitation Research. The opinions expressed do not necessarily reflect the views of the University of Minnesota or its funding sources.*

Children's Health Notes
Box 721
420 Delaware St. SE
Minneapolis, MN 55455
(612) 626-4032 V
(612) 624-3939 TDD

Do You Know Who Pays the Bills?

Chances are if you have a child with a chronic illness or disability who receives special education services, you may have a tough time sorting out that question.

You can usually figure out what comes "out-of-pocket." That's the cost of insurance premiums, co-payments and deductibles and any adaptive equipment or special service not covered by a program.

Some of the funds come through local, state and federal education. Some bills may be paid by your insurance company or HMO. You might receive state and federal aid through Medial Assistance or Medicaid. You may pay for Medical Assistance as a "secondary" insurance plan. The county you live in may provide respite dollars or perhaps a pre-school subsidy. Organizations like the Shriners or the Lions Club may contribute to the cost of services and equipment. In each case, your child "qualifies" for support based on the criteria of the funding source. It's a tangle.

Here's a list of services many families need. Who pays for them at your house? How much paperwork must you do? Perhaps its time to talk single funding source.

Health care professionals _____

Insurance premiums _____

Hospitalizations _____

Co-payments and deductibles _____

Durable medical equipment _____

Prescription drugs _____

Hearing aids or glasses _____

Special supplies _____

Home modifications _____

Special van or automobile _____

Special education services _____

Special recreational programming _____

Specialized child care _____

Respite care _____

Personal care attendant _____

Health education _____

Communication technology _____

Other _____

The Hassle Factor

By Peggy Mann Rinehart

You can get a jump on health care reform by taking stock of the services your family and your child with a chronic illness or disability currently receive, and who provides them.

Here are some questions you may want to evaluate on a scale of one to five to take stock of your current health care status.

1. My child and family receive all preventive or primary health care, including immunizations, well-child check-ups, developmental, treatment, mental health care and support services.

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

2. My child's school, health and medical, social or county services assessments are based on the things my child does every day (activities of daily living). Our physicians, teachers, therapists, social workers and other providers deliver services based on what our child can do.

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

3. List the name and telephone number of each case coordinator, case manager, or other person who recommends, assesses or approves services for your child. How many do you have?

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

4. List the name and number of the person(s) you call if there is an emergency.

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

5. Our teachers, physicians and social workers have a good understanding of the educational, medical and social services our child receives. They understand our child's needs, communicate, and coordinate services with one another.

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

6. We are able to identify funding sources and/or pay for the services for our family.

Little Hassle ..... Huge Hassle

0	1	2	3	4	5

SCORING:

Add up the number answered in each of the questions to determine your "Hassle Factor." If your score is less than 10 points: You and your family have a remarkable handle on the services you need. Protect it!

If you score between 10 and 20, you're struggling to get and keep the services you and your family need. If you score more than 20 points, like most of us, you are trying to figure out how to get access to quality and equitable health care services from inefficient systems and fragmented providers.

Seven Ways to Reduce the Hassle Factor

Local and state debates regarding health care reform may provide a good forum to discuss streamlining, coordinating and individualizing services for children and youth with chronic illness or disabilities and their families. Here are some ideas:

- ***Assessments*** Develop one standardized assessment for children and families to identify level and types of services.
- ***Functional Definitions*** Ask that your care plan be based on the needs of your whole child and family, not just on the disease or chronic condition.
- ***Coordination*** Coordinate services at a federal, state and local level. Limit the number of people responsible for coordination of care for individual children.
- ***Partnerships*** Teach and empower parents to become their child's service coordinator. Develop a PTA equivalent for health care services.
- ***Training*** Integrate pre- and post-professional training of educators, health care providers and social service providers.
- ***Continuing Education*** Universities and medical schools should make room for community/parent consortium to develop courses, some of which are required for recertification or relicensure.
- ***Financing*** Untangle the funding streams by standardizing qualification criteria and let funding follow the child rather than forcing the child to chase after the funding.

A Window of Opportunity

Times of change produce windows of opportunity, and that may be true for children and youth with disabilities during the debates on health care reform.

The Center for Children with Chronic Illness and Disability was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

Who would have predicted the *Wall Street Journal* would publish a letter written by the mother of a child with multiple disabilities, detailing the nightmares of managing the three bureaucratic systems of care for her child: school, social service and health? But they did, on January 6, 1994, when they published Marrianne M. Jennings' letter, "A Mother Talks to Mrs. Clinton."

Ms. Jennings details her frustration as she introduces Mrs. Clinton to the five or so caseworkers assigned to their daughter. "One is from Arizona's Department of Developmental Disability. Another is with the Arizona Long Term Care. Another is with the Arizona Health Care Cost Containment System. Another is with APIPA, and I don't know what that stands for. I lost track of acronyms, agencies and caseworkers long ago."

"... I am a lawyer who teaches and writes about administrative process. Yet this system is beyond my expertise. How do parents with language barriers, little or no knowledge of due process, and noncompulsive personalities cope?"

Now is the time to make your concerns known about health care reform and your child with disabilities. Make a list of all your questions and concerns, then write or call your local newspaper, television news program, congressional person or senator. Health care reform is news these days, and who is better able to talk about health care than those of us who have been trying to coordinate the care for our children with chronic illness or disability.

Health Policy & Chronic Illness

From page 51

- Move **health care reform** towards providing health care for children and youth that includes preventive, developmental, treatment and support services.
- Streamline **service systems** so that each child or youth and their families who require multi-agency, multi-provider assistance have a "Service Home." This would centralize care coordination for families and bring together educator, physician, nurse, social service provider and parent, along with appropriate mental health professionals, vocational counselors and others as appropriate to individual needs.
- Provide pre-service and **continuing education** for health, education, and social services professionals who work with children with special health care needs and their families.
- Restructure **financing of services** so that funds are flexible and based on the needs of the child and the family rather than those of the agency.
- Provide centralized, comprehensive, **multi-disciplinary resources** for providers working with children and youth who have chronic and disabling conditions.

The Center for Children with Chronic Illness and Disability, the National Center for Youth with Disabilities, along with the Institute for Disabilities Studies of the University of Minnesota, the American Academy of Pediatrics, LaRabida Children's Hospital and Research Center of the University of Chicago and the Ka.. nd Endowment Fund of The Johnson Foundation, Inc., sponsored this special working conference.

A summary of the proceedings, key recommendations, and final copies of the papers presented will be presented in an academic journal. Material will also be disseminated by Children's Health Issues published by the Center.

Selecting a . . .
Summer Camp

Enrolling your child in a summer camp can be a rewarding experience for all concerned. *Exceptional Parent* asked camping experts what parents can look for when considering a summer camp.

At the outset, it's important to know what your child needs when evaluating camp programs. Be aware of your child's interests, capabilities, strengths and weaknesses, and consider programs accordingly. Ask about the goals of the camp by writing or calling the camp director. What is a typical day at camp like? What happens when the weather is bad? Can needed therapies be provided by trained staff?

Check the accreditations of the camp. Find out how many years the camp has been in operation—a camp with a longer history has probably learned how to meet children's special needs under varying circumstances.

Inquire about references—many camps will be happy to provide them, and the perspective of another parent can be very helpful. If possible, visit the camp to assess whether the environment is suitable to your child's needs. Ask about the quality of the accommodations—do the cabins have foundations? Are the tents on platforms? Are the water and toilet facilities monitored by local or state health departments?

Consider the age range of the campers, and check how they will be grouped. Ask if a camper "report card" or summary of activities is available at the end of the sessions. Do the activities reinforce skills learned during the rest of the year?

The staff is also an important consideration. Check the staff-to-camper ratio, as well as the supervisor-to-staff ratio. Are the staff experienced and trained in working with children with special needs? Does the camp use overnight staff to monitor camper safety? Are the staff trained in first aid and special health care needs? Are they knowledgeable in the care and maintenance of adaptive equipment?

In the swim: *Counselors at Heartspring assist campers.*

Another important factor to consider is medical needs. What are the camp's health services like? How is medication dispensed? Is there a full-time nurse or infirmary on-site? If not, is there a clinic nearby in case of emergencies?

Transportation is another issue. If the camp offers transportation for campers, are the vehicles and drivers properly licensed?

If possible, check out a variety of camps to find the one that appears best able to meet your child's needs. ■

—A.B.

Thanks to the following for their contributions to this article: Sonya Richards, Camp Amigo, Sturgis, MI; Tom Bauer, Director, Camp Buckskin, Ely, MN; Bruria Bodek-Falik, Ph.D., Director, Camp Huntington, High Falls, NY; Raymond W. DuCharme, Ph.D., Director, The Learning Clinic, Brooklyn, CT; Lee Morrone, Director, Le Mar, New York, NY; Ron Eydt, Director, Tall Pine Camp for Exceptional Citizens, Tellico Plains, TN.

The ABLEDATA Database of Assistive Technology

by Alynne Landers

While parents of children with disabilities are never totally prepared for the challenges they will encounter, assistive technology and adaptive equipment can resolve some of these challenges. Assistive technology can provide a means for children to be more independent, or to participate in activities with friends who do not have disabilities. However, the process of identifying the assistive technology product needs of each child is often easier than actually locating the equipment to accommodate those needs—and the parents' budget!

ABLEDATA is a single, comprehensive resource that parents can use to locate and compare assistive technology products. The number of choices available may surprise even the most well-informed. For example, ABLEDATA has information on nearly 900 products to make a home safe and accessible—including 353 products just for the bathroom! There are 310 computer-assisted instruction programs for students with disabilities, 126 adapted toys and 191 games designed for kids and teens with disabilities. In fact, ABLEDATA has information on more than 19,000 products!

ABLEDATA provides an internationally renowned database of information on assistive technology and rehabilitation equipment for all disabilities and all age groups. The project maintains and adds new records on products currently manufactured and distributed in the United States from approximately 2,500 domestic and foreign companies. In addition to commercially available products, the database also includes nearly a thousand "Do-It-Yourself" designs and prototype descriptions. Covering high-tech, low-tech and "no-tech" products designed for persons with disabilities, the scope of the database ranges from enlarged-handle utensils to the most sophisticated optical-character recognition devices (computer screen readers).

Entries in the ABLEDATA database includes manufacturer and distributor information for each product, product features and specifications and pricing data in a format that permits easy comparison among products.

If you haven't used ABLEDATA lately, you don't know ABLEDATA!

ABLEDATA was started more than ten years ago by Marian Hall, an occupational therapist. Over the years, this collection of data has expanded from a manual system of boxed files to an extensive, recognized authority on assistive technology terminology and classification. ABLEDATA has evolved into a premier information and referral system available to individuals with disabilities, their parents, siblings or spouses, rehabilitation professionals, disability advocates and businesses looking to comply with the Americans with Disabilities Act (ADA).

Today, under the management of Macro International Inc., this data collection has reached "the next generation" with multiple computer-linked databases that provide immediate updates of information and terminology changes; an electronic bulletin board system—ABLE INFORM—and an IBM CD-ROM in Windows and DOS formats for personal computers. Parents who contacted ABLEDATA in the past are encouraged to access the system again to see all the quality, user-friendly enhancements implemented in the past two years.

ABLEDATA Product Areas:

- Architectural Elements
- Communication
- Computers
- Controls
- Educational Management
- Home Management
- Orthotics
- Personal Care
- Prosthetics
- Recreation
- Seating
- Sensory Disabilities
  - Blind & Low Vision
  - Deaf & Hard of Hearing
  - Deaf/Blind
- Therapeutic Aids
- Transportation
- Vocational Management
- Walking
- Wheeled Mobility

Tapping into ABLEDATA Resources

- *Online: ABLE INFORM:* With a modem and telecommunications software package, computer users can call this electronic bulletin board service 24-hours a day to search the database directly, to leave/receive messages in the conference areas or to download ABLEDATA fact sheets. Computer dial 301-589-3563 (1200 to 9600 baud, N-8-1). There are no subscriptions fees; cost is based on the phone call from the user's station to the ABLEDATA office.
- *IBM CD-ROM:* ABLEDATA is now available on CD-ROM for use on IBM personal computers, and compatible with Windows™ and DOS formats. Prompts and pop-up windows permit even novice computer users to search the database by product name, company or product type. Electronic images of many products can be displayed on the screen using the "Picture" option. Yearly subscriptions (2 CDs per year for $50) are available beginning in the Spring of 1994.
- *Call, write, fax, visit:* For non-computer users, ABLEDATA services are also available through these options. Both local and toll-free lines are voice and text telephone (TDD) compatible. For patrons living in or visiting the Washington, DC area, a personal guided tour of the center can be scheduled upon request. Contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD, 20910, (800) 227-0216, (301) 588-9284, (301) 587-1967 (FAX). ■

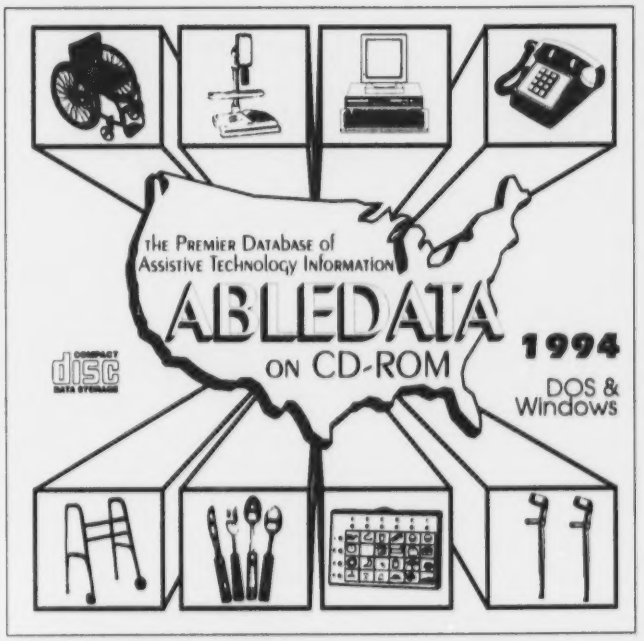
Alynne Landers, M.I.M., is a program specialist at ABLEDATA.
ABLEDATA is funded by the National Institute of Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, contract no. HN92026001 and managed by Macro International Inc.

The ABLEDATA IBM CD-ROM is here!

The master version of the database is now available in Windows™ & DOS™ formats

Information at Your Fingertips

- ☑ More than 19,000 product entries in all
- ☑ Electronic images of 1,000+ products
- ☑ 2,400 domestic and foreign manufacturers and distributors
- ☑ Nearly 800 Do-It-Yourself designs
- ☑ Commercially available products
- ☑ Non-commercial technology including prototypes
- ☑ Manufacturer stated ADA compliance information
- ☑ End-user and clinician comments on products
- ☑ An historical and research reference of discontinued products



To order your personal copy of the ABLEDATA CD-ROM, call 800/227-0216

A Resource for Professionals & Parents!

The ABLEDATA project is proud to announce the release of the 1994 version of the ABLEDATA database of assistive technology and rehabilitation equipment on CD-ROM or diskettes for IBM and compatible computers. This resource empowers your IBM PC with information on products for children and adults with physical, sensory, and/or cognitive disabilities. The information contained in this database can shed light on providing barrier-free solutions to accessibility issues, can identify products made specifically for children or adjustable to child sizes, and can help parents locate products which will assist their child at home, in school, and during play!

Each record in the database contains:

- manufacturer and/or distributer information
- pricing information
- a complete description of the product

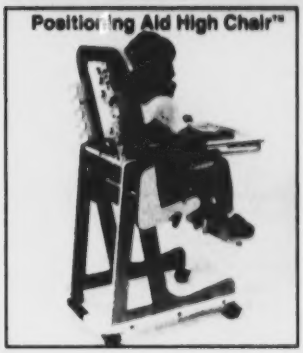
Each abstract is written so that both rehab professionals and laypersons can understand the features and function of the product.

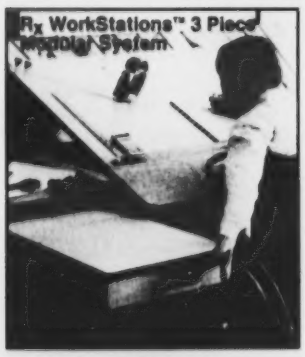
Architectural Elements • Blind & Low Vision • Alternative & Augmentative Communication • Computers: Hardware & Software • Controls • Deaf & Hard of Hearing • Educational Management • Home Management • Orthotics • Personal Care • Prosthetics • Recreation • Seating • Sports • Therapeutic Aids • Toys • Transportation • Vocational Management • Walking • Wheeled Mobility

8455 Colesville Road, Suite 935, Silver Spring, MD 20910

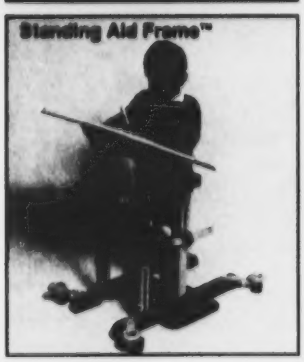
The ABLEDATA project is funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education (contract HN92026001), and managed by Macro International, Inc.

SEE OUR ***NEW*** AND ***EXPANDED***
CATALOG
FOR THESE ITEMS AND MORE





PLEASE ASK CUSTOMER SERVICE ABOUT OUR . . .
☐ Free Catalog with 100 plus products & accessories ☐ Trial Use Program ☐ Lease/Rentals ☐ Factory Outlet Store ☐ One Year Warranty ☐ How To Order Direct or via an Authorized Dealer

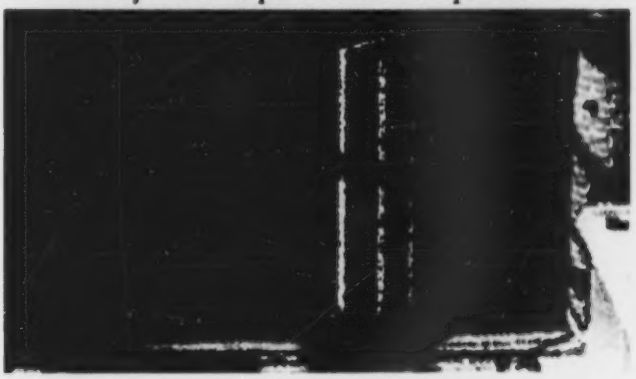


Consumer Care Products Inc.
810 N. Water St., P.O. Box 684
Sheboygan, WI 53082-0684
Tel: 414-459-8353 FAX: 414-459-9070
Since 1978
Circle #111

For people with disabilities,

WE CAN

turn your computer into an open door.



A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3333 (TDD); in Canada, 1-800-465-7999.

At IBM, we can do more than you think.

Circle #121 IBM INDEPENDENCE SERIES

© IBM Corp. 1994. ® IBM and Independence Series are registered trademarks of International Business Machines Corporation.

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27

Judy Heumann

Part Two

OSERS chief discusses her vision for the future

Judy Heumann, Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS), U.S. Department of Education, was interviewed by Exceptional Parent *in December 1993. An activist and policy-maker, Heumann worked on Section 504 of the Rehabilitation Act and its reauthorization, the Individuals with Disabilities Education Act, the Americans with Disabilities Act and federal policy guidance governing the provision of personal assistance services to individuals with significant disabilities. She was the first wheelchair rider to be hired by the New York City public schools. Heumann was also co-founder and vice president of the World Institute on Disability, a public policy/research/training organization. This is the second part of our interview with Heumann; Part One appeared in February 1994.*

In 1973, I went out to California to attend graduate school because I needed a masters degree to go on in teaching. While I was going to school for my masters in public health and administration and planning, I got involved with the country's first independent living center—the Center for Independent Living in Berkeley.

Going to California was the beginning of another part of my life. I had left my whole family back in New York. I was never really happy in California; I liked the work, but I missed New York. It was a valuable experience for me, however, because it was a smaller, more progressive community. I could use what I had learned in New York to do some very exciting work in California.

> *"I want to get people to work more effectively together–regular education and special education; employers and rehabilitation agencies; parents, children and adults with disabilities."*

After about seven years, I left California and came to Washington where I worked for Senator Harrison Williams for about a year and a half. Among other things, I worked on the Education for All Handicapped Children Act. After that, I went back to California and worked for the State Department of Rehabilitation. And I worked for the State Rehabilitation Agency for about eight months. I went from rehab client to rehab worker. I have been involved in many different activities over the years. I think this has given me a broad base of experience for my job at OSERS.

The role of parents

I have a lot of respect for the role that parents can play. Back when I was working at the Berkeley Center, I helped set up a number of programs that involved parents in independent living. At that time, there was a lot of disagreement among disabled adults about parental involvement. Many people felt that parents of children with disabilties tended to be overprotective. Rather than helping, they were part of the problem. I did not agree. I felt that parents needed education just like anyone else. If we could reach parents early enough, they could be very influential not only in the lives of their children, but in the disability rights movement itself.

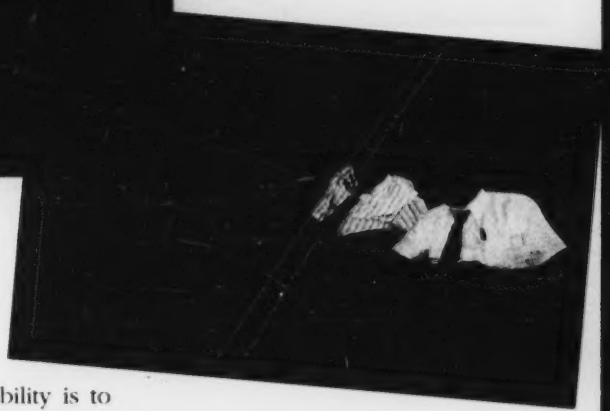
Ultimately, I think it is important that parents see their children with disabilities simply as children. Interactions with the medical community frequently cause parents to have difficulty recognizing that their child with a disability is just like a child without a disability. Their child with a disability needs the same kind of love and support and direction. I think it is very important that parents have high expectations for their children. I also think it is important for them to ensure that their kids are being taught academic skills *and* independent living skills from an early age.

> *I hope that one of the messages that I provide is that disabled girls can grow up and be powerful disabled women.*

Top: Judy Heumann, with eleven-year-old Jennifer McKeown of Haddon Heights, N.J.

Center: Judy Heumann, at her swearing in as Assistant Secretary, pictured with Ed Roberts (left) of the World Institute on Disability, his son Lee (center) and Joan Leon (right), also of WID.

Below: Judy Heumann, with independent living advocates (from left) Chester Helms, Paul Spooner and Larry Robinson.



Challenges at OSERS

My position here is very challenging because it involves coordinating the three components of OSERS—Special Education, Rehabili-tation and the National Institute on Disability Rehabilitation and Research. These three elements together allow me to work with staff and constituency groups around the country to set up systems that will enable children and adults with disabilities to receive appropriate services and become integrated members of their communities with the ability to obtain competitive employment.

This is one area where my background helps me; I have broad experience working with many different constituency groups. That enables me to be sensitive in addressing the needs of diverse groups—from the perspectives of both disability and culture.

At OSERS, I have a staff of more than 400 people and a budget of roughly 5.5 billion dollars. OSERS has the legal obligation to monitor special education around the United States.

I see my responsibilities here as being multiple. One is simply getting OSERS to work, getting the three components to work together and develop effective plans. An equally important responsibility is to work with groups around the country to help them recognize the important role that they need to play in helping us to set our agenda.

I am also working to elevate issues affecting disabled children and youth throughout the entire Department of Education. The needs of disabled children and youth should not be perceived as only the responsibility of OSERS; rather the Department as a whole is responsible for them.

I want to get people to work more effectively together—regular education and special education; employers and rehabilitation agencies; parents, children and adults with disabilities. My work in OSERS is part of an overall civil rights agenda that the disability community has been involved in for many years. For the last 12 years under the previous administrations, OSERS, the Department of Education and the government as a whole was not allowed to be at its best. I believe that many of the problems states are now facing came about because previous administrations did not provide appropriate technical assistance and other support. They didn't monitor states in a way that would allow them to understand that we can provide technical assistance and support, but that we also expect them to live up to the letter and spirit of the law.

Right now we are beginning the process for reauthorization of the Individuals with Disabilities Education Act (IDEA). We are seeking the input of organizations and individuals on various issues within the IDEA. We want to know people's concerns, and we would like them to make recommendations for changes. Basically, we believe that the IDEA is a very solid piece of legislation. The types of changes that we will consider will be changes that will make the law even stronger.

Diversity issues

I bring two important characteristics to this job—I am disabled and I am a woman. I think when we look at statistics, we find that disabled girls and women fare worse than disabled boys and disabled men, who fare worse than non-disabled boys, non-disabled men, non-disabled girls and non-disabled women.

I hope that one of the messages that I provide is that disabled girls can grow up and be powerful disabled women. Parents need to do everything they can to wipe out sex bias against girls with disabilities in the same way we are working on that issue for non-disabled girls.

I also feel a strong responsibility to work on issues affecting minority children and adults. I think that Congress has given us very clear directives to provide more effective services and assure better outcomes throughout the entire population. I have a very strong commitment to making this happen. I think that OSERS staff members are learning how to work more effectively with groups outside the government. And I think outside groups are learning how to work with us.

There is a big move in this country for diversity—being sensitive to racial and cultural differences, making sure that boys and girls are treated equally. But often in the case of children and adults with disabilities, we're not appropriately reflected in textbooks or in the media. When we show up in books or on television, we are treated as special. Personally, I don't like the word "special." All children are special! It is important that people with disabilties are reflected more accurately in children's literature. That's not just something that disabled children need to see; non-disabled children need to see it too. We need to help children accept the fact that people with disabilities are becoming a larger and more influential part of society.

Looking Forward

During my tenure as Assistant Secretary, OSERS will aggressively and collaboratively work to create a society in which all disabled people can obtain the knowledge and skills necessary to achieve the goals they set for themselves. This vision can lead us into the 21st century in a way that builds on our past accomplishments, embraces the spirit and intent of our statutes and regulations, focuses our strategic planning process and drives the work we do each day. I believe it also moves us toward the society President Clinton envisioned when he pledged to work for "inclusion not exclusion, independence not dependence, and empowerment not paternalism." I look forward to working with all of you in this important effort. ■

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

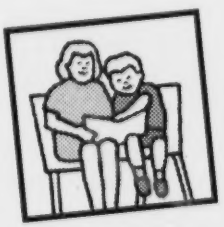
For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

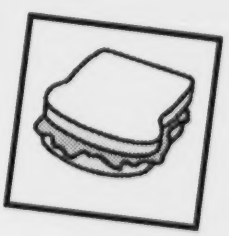
Circle #75

imaginart

Let us help you and your child with friendly, high quality materials:



- picture communication
- feeding and swallowing
- language development *featuring the Hanen Program*
- toys and games to train daily living skills



Pictures shown are communication stickers from our Pick 'n Stick Primary Pack.

Call or write for our free catalog:
Imaginart Communication Products
307 Arizona Street, Dept. EP4, Bisbee, AZ 85603
(800) 828-1376

Circle #41

Rachel, Say 'Hi'

by Paul J. Karch

"Rachel, look who's here—Daddy. Say, 'Hi' to Daddy."

"Hi, Rachel. Good morning."

"Rachel, say, 'Hi' to Daddy."

She doesn't say it. She never says it in the morning, although she occasionally does at other times. She's clearly excited to see me still here. I can tell she's excited because she's dancing around on her toes with her elbows straight out, waving her forearms in the air, like she was trying to shake water off them. She looks sweet in her pajamas and her excitement. But that dancing and hand shaking is one of the things kids do when they make fun of kids who have retardation.

I don't usually think of Rachel as looking or acting as though she has a disability. Maybe I just don't notice, because she's Rachel. When she was a baby and swollen from her seizure medicine, my wife and I told each other she was beautiful and we saw that she was. Now, it hurts to look at those pictures, because her flesh looks like it's trying to burst out of her skin and her eyes are listless. Of course, now she really is beautiful.

"Rachel, are you ready to eat breakfast? Say, 'Hi' to Daddy."

She doesn't say it. She doesn't look at me either. She does look at me sometimes. She takes my head in her hands and looks directly into my eyes without holding anything back. People who aren't used to her can't take it. It's the kind of searching look that lovers and long-separated parents and children give each other in novels and movies, a warm, lively look that makes you feel special and glad to be alive, but so intense and searching that after a while, you are afraid that you can't give her what she is looking for.

Family portrait: *(left to right) Paul, Rachel, Lydia (seated), Anne and Charlie.*

For a long time, she wouldn't look in people's faces. It was those eyes that first made us wonder if something was wrong with our baby. Then, for a time, she was willing to look into dogs' faces, but not people's. By the time we got a dog for her to look at, she was more interested in people.

"Rachel, keep the cottage cheese on the spoon. Have you said, 'Hi' to your daddy yet?"

She doesn't say it. The cottage cheese is falling off the spoon because she is turning her arm back and forth to admire the morning sun and shadows moving across it. She likes that game, one of her private games that we can recognize, but can't share. It makes her smile. She smiles her secret smile, the expression that makes you think she has just thought of a mischievous trick, but she won't tell anybody until she's played it.

We have a picture of her first real smile. I am holding her in the shower during the summer she turned one. I can see that picture in my mind at any time. That smile brought the sun through the dark clouds for us. We had worked hard to help her, but we didn't know if we had the strength of character to love and live with a child who never smiled. Some people do. God didn't require that of us. That day, she smiled and we cried.

Now, she smiles a lot, most often if you tickle her or if she's jumping on her trampoline, riding her tricycle or doing something else that involves "major sensory input," as her therapists say. She also smiles sometimes when I come home from work and when she hears a funny noise that she likes, like the pig grunting, "Touché," in *Beauty and the Beast*. But she doesn't smile much at things that make most kids smile, like playing peek-a-boo.

"Rachel, would you like some Crunch?"

"Cwunch, peese."

She can talk. She likes to use her language for a purpose. She was the star of "meaningful communication" when she was in the special education preschool class for kids with autism. When Rachel "talks," you know she is trying to tell you something, even if most of the time you don't know what. We wonder if there are other ways to help her converse that don't rely on precise control of small, working parts, like a tongue and lips. We offer her those other channels, but Rachel seems to prefer battling it out with the spoken word. If she says something often enough and takes the uncomprehending listener by the hand to the place or object, we feel like we understand what she's trying to tell us. But there are still plenty of times when she repeats herself with enthusiasm and a strong desire to let us know and we just don't get it. Eventually, she sighs and moves on.

Sharing a moment: *Dad and Rachel.*

Some parents of children with disabilities grieve continually for the loss of the normal child who might have been. I don't feel quite that way. Rachel is the child she is, and I don't think much about who she might have been. But when she sighs and gives up because I don't understand, then I grieve.

"Rachel, calm down and use your words. Use your quiet voice."

Of course, she doesn't always give up when she isn't understood; sometimes she has a tantrum. It's often hard to figure out what sets her off, and it's always hard to decide what to do next. Colleagues and friends who don't know Rachel tend to say things like, "Well, I've got a 15-year-old in my house who still has tantrums." It is not the same. Having thought about this at length in an objective, scientific manner while my blood is racing, my ears are pounding, and my hair is being pulled out of my head, I conclude that there is a fundamental difference between a "regular" child's tantrum caused by hunger, fatigue or a fine sense of dramatic manipulation and Rachel's tantrums caused by her rage at the world's failure to understand her or explain to her why she can't have what she wants. Then again, maybe it's just a two-year-old's tantrum in a seven-year-old body.

"Rachel, Daddy is leaving. Can you say 'Bye-bye Daddy?'"

She doesn't say it. She doesn't really even look up when I leave, although I'm told that she sometimes runs around the house shouting, "Daddy! Daddy!," after I've gone. Some friends and acquaintances think we're heroes for "all we've done" for Rachel. Others would rather not think about it at all. I don't feel like a hero, because I didn't volunteer for this job. Most of the time, I'm not sad about Rachel because she learns, loves and is often happy. But sometimes, in the morning as I prepare to leave for work, I hope that she will say "Hi, Daddy." ■

Paul J. Karch is a lawyer and the father of three children: Rachel, seven; Lydia, five; and Charlie, two. Paul and his family live in Appleton, Wisconsin, where he works in the legal department of Appleton Papers. He enjoys spending time with his family, bicycling and reading. Rachel was born with a chromosomal abnormality and has a severe cognitive disability. Rachel and Lydia attend Janet Berry School in Appleton, a school that promotes the full inclusion of all children.

Fathers' Voices *is a regular feature of* ***Exceptional Parent*** *magazine. This column, coordinated by James May, Project Director of the National Fathers' Network, focuses on fathers' experiences raising children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth Street, Bellevue, WA 98008, (206) 747-4004 or (206) 282-1334. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with the National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda, MD.

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or Product & Service listing or refer to the Directory of Advertisers.

2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.

3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.

4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

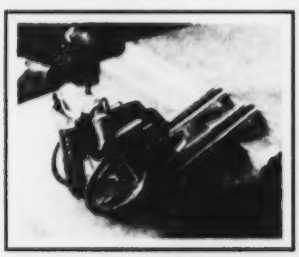
EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

Rollup/3' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

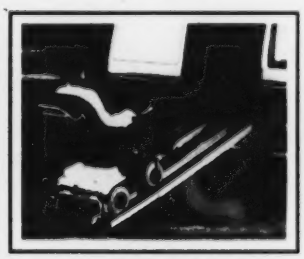
- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

Look for this Seal of Quality



R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle #40

DIRECTORY OF ADVERTISERS

Circle #	Advertiser	Page #
	Abilities Expo	40
#170	Aquatic Therapy	65
#7	BHC JA Preston	back cover
#6	Berkshire Meadows	39
#115	Braun	27
#8	Bruno	25
#10	Charles C. Thomas	75
#11, 12	Columbia Medical	8, 36
#111	Consumer Care Products	58
#16	Convaid	20
#17	Crotched Mountain	79
#114	Crow River	inside back cover
#151	Crystal Springs	49
#18	Cumberland Hospital	44
#19	Devereux	9
#26	Estate Planning	36
	Exceptional Parent Library	76
#27	Evergreen	58
#30	Ford	inside front cover
	Genral Motors	13
#201	Global Export Marketing	67
#39	HMS School	39
	Hackensack Medical Center	32
#36	Haverich Ortho-Sport, Inc.	10
#38	Heartspring	16
#40	Homecare Products	64
#121	IBM (Special Needs Project)	58
#41	Imaginart	61
#42	Innovative Products	42
#200	Interior Planning & Design, Inc.	67
#44	Jay Medical	3
#45	Kennedy Krieger	10
#46	Kid-Kart	26
#48	Laurette Learning	49
#167	Medical Innovations	5
#168	Merrill Lynch	7
#169	Milani Foods	15
	NMEDA	68
#123	PI Bear	50
#161	Pathfinder	50
#60	Phonic Ear	35
#103	Rhamdec	26
#92, 93	Quickie Designs	17, 29
#103	Rhamdec	31
#65	Ricon	22
#67	Rollins Healthcare	46
#74	St. Colletta (WI)	49
#75	St. John's Villa	61
#68	Sentient Systems	39
#69	Snug Seat	21
#71	Special Design	50
#78	Stroller Pack	46
#122	TMI	43
#82	Triaid	65
#75	Voorhees Pediatric	32
#165	Wheeling Free	28
#62	Willow River Farms	36
#86	Woodbury Products	32

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: March 31, 1994

Expiration Date: June 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: March 31, 1994

Expiration Date: June 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

EXCEPTIONAL PARENT

Parenting Your Child With a Disability

Vice President Advertising Sales
Kerry J. Cannon
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/
Fax (201) 489-1240

Sales Representatives

Greater New York - Joni Jones
Phone (516) 944-8068/Fax (516) 944-2739

New Jersey, Schools, Camps, Residences, Classified & Special Sales - Barbara Nastro
Phone (201) 680-4874/Fax (201) 680-8355

New England, Upstate NY and East Canada - Barbara H. Arnold
Phone (617) 259-9207/Fax (617) 259-9883

MidAtlantic (DE, DC, MD, PA, VA, WV) - Kerry J. Cannon
Phone (201) 489-0871/Fax (201) 489-1240

Southeast (AL, FL, GA, MS, NC, SC, TN) - William Middleton
Phone (404) 973-9190/Fax (404) 859-0051

Midwest (IN, KY, KS, MN, ND, OH, SD, UT, CO) - Anthony Arnone
Phone & Fax (708) 428-5162

Midwest (IL, IO, NE, MO, MI) - John Maisel
Phone (708) 416-0780/Fax (708) 416-0793

Southwest (AZ, NM, TX, OK, LA, AR) - Sherylen Young
Phone (602) 991-2889/Fax (602) 596-4026

West Coast (So CA, NV) - Richard Ayer
Phone (714) 366-9089/Fax (714) 366-9289

West Coast (No CA, OR, WA, HI, BC) - William Hague
Phone (206) 858-7575/Fax (206) 858-7576

Ad Traffic Manager
Stefanie Ferrante
Exceptional Parent
120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)/Fax (201) 489-1240

BPA International Consumer Magazine Membership Applied for August 1993.

Subscriptions:
Exceptional Parent
P.O. Box 3000, Dept. EP, Denville, NJ 07834
(800) 247-8080 (New subscriptions ONLY)
(800) 562-1973 (Customer Service)

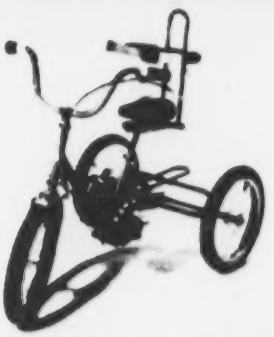
Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute or imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

The Very Best Europe Has To Offer!



At American Prices.

TRIAID
REHABILITATION PRODUCTS

301-759-3525

P.O. Box 1364 Cumberland, Maryland 21502

VISA-MasterCard Now Available

Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle #82

* Improves coordination, postural control and muscle tone.
* Provides independence.
* Secured in center with belt or seat.
* Trade-in policy.
* S,M,L
* Covered by most insurance companies.

THE WATER WALKER

* Prone or supine support.
* Contour lines that allow use of arms and legs.
* Straps to secure person on float.
* Pillow for head support.
* S,M,L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
123 Haymac Street
Kalamazoo, MI 49004
(616) 349-9049

VISA MasterCard

Circle #170

Brain Differences in Autism

by Margaret Bauman

My research colleague, Dr. Thomas Kemper, and I have been studying the anatomy of the brain in autism. We began these studies in the summer of 1983, and reported our initial findings at the meeting of the American Academy of Neurology in the spring of 1984. Since then, we have studied a total of six cases in detail.

Dr. Margaret Bauman, pictured with her family.

Method

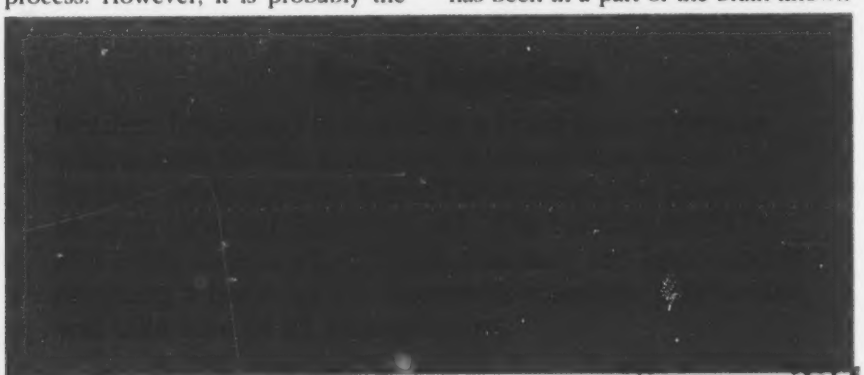
Our research involves the examination of human autopsy material. This material has been very generously donated by the families of children and young adults with autism who have died as the result of illness or injury. It is essential that we use human brains for this research because, at this time, there is no experimental animal model that could be utilized.

For the purpose of comparison, each autistic brain is matched with a "control"—the brain of a non-autistic person who was the same sex and age. We study each brain by cutting it into approximately 4000 thin slices, or "sections," cut from front to back. Each brain is examined, section by section and area by area. We use a special microscope that allows us to put the same sections of the autistic brain and the normal brain side by side in the same field of view and at the same magnification. Of course, this is a very tedious and time-consuming process. However, it is probably the best way to survey an entire brain, especially when the findings may be subtle and difficult to spot, as has been the case in some portions of the autistic brain. In fact, without this methodology, we probably would not have been able to identify some of the unique anatomical differences in autistic brains.

Limbic System Abnormalities

One abnormality that we have found has been in a part of the brain known as the limbic system. The limbic system includes a number of brain areas that are connected to each other by neuronal circuits. The limbic system appears to play a significant role in human learning, emotion, behavior and memory. In autistic brains, the nerve cells of the limbic system are smaller and more numerous than those found in normal controls. In this respect, the autistic limbic system is like that of a younger child. This might mean that the development of the limbic system is stunted in individuals with autism.

With regard to memory, there is evidence that we have at least two types of memory systems that are involved in learning. The first type is called "habit" memory. We use this kind of memory to learn skills—tying our shoes, catching a ball, riding a bicycle. The "habit" memory system is believed to reside in areas that we have found to be anatomically normal in autistic brains.



234

The second memory system is called "representational" memory. This kind of memory is involved in organizing sensory input—what we see, hear and feel—generalizing and integrating information gained from sensory input to think and reason. The "representational" memory system is believed to depend on parts of the limbic system. Limbic system abnormalities, such as those found in autistic brains, could lead to a disturbance in the processing of sensory information. This, in turn, could lead to the disordered thinking, social interaction and language that is characteristic of infantile autism.

Cerebellar Abnormalities

We have also found abnormalities in the cerebellum and cerebellar circuits of the autistic brain. The types of abnormalities that we have found indicate that, whatever the cause, the damage to the brain occurred prenatally, before thirty weeks gestation.

Future Plans

I believe that we have identified the most obvious structural abnormalities, but we will continue to look at new brains and re-examine our older material. We have been able to create a "library" of slides to go back to as new research questions arise. For example, if we observe a previously unrecognized abnormality in a new case, we can go back and re-examine our previous cases to see if the abnormality is unique to this new case, or if it is present in all of the autistic brains but had been previously overlooked.

We are also interested in neurotransmitter function in autism. Now that we know the location of structural abnormalities, the next step will be to investigate the neurochemical profile of these same areas. We have the technology to do this. We also have the necessary brain material from autistic and normal individuals. All we need now is money!

The potential for this type of study could be enormous. If we are able to identify one or more neurochemical abnormalities, this might give us a chemical "marker" for autism. This marker could be used in diagnosis—prenatally or postnatally. Identification of a chemical abnormality could also lead to more directed medical intervention and treatment. I don't know if we will be able to "cure" autism, but we should be able to improve function and the quality of life significantly. That would be a truly exciting outcome!

Parental Involvement

If I had one wish it would be that parents become stronger advocates for the basic scientific research that may solve the mystery of autism. Good research is being done throughout the United States, and it is very deserving of support. Good research requires money, but right now, autism researchers must compete with each other for a limited supply of funds.

Parents need to lobby at a national level for their children. If parents don't do it, it simply will not happen. Children don't vote. They have no political clout. We, the adults in their lives, must speak for them. If we do not speak out, nobody will, and the future for these children will be less bright. ■

Dr. Margaret Bauman is Assistant Pediatrician and Assistant Neurologist at the Massachusetts General Hospital, and Assistant Professor of Neurology at Harvard Medical School. She is also Director of Learning and Developmental Disabilities Evaluation and Rehabilitation Service (LADDERS), at Youville Hospital in Cambridge, MA.

INTERIOR PLANNING & DESIGN, INC.

Custom designed to your needs:
Institutional, Home,
Office,
Health Care.

Turnkey operation, including furniture,
U.S.A. and International.

2 Annabelle Lane
Florham Park, NJ 07932
(201) 966-0220
Fax (201) 966-6894

Circle #200

GLOBAL EXPORT MARKETING (GEM)

Representing Exceptional Parent
Internationally:
Books,
Magazines,
Information Equipment.

2 Annabelle Lane
Florham Park, NJ 07932
(201) 966-0220
Fax (201) 966-6894

Circle #201

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New England Wheels West, Inc.
15F International Drive
East Granby, CT 06026
(203) 653-8064
Custom builders for physically challenged drivers. Large inventory of new transporters for ambulatie and school, institution and transportation. Call to see demonstrator.

Florida

Action Mobility
1925 10th Ave. No.
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 in FL
Full or Mini-Van modifications. Scooter & wheelchair lifts, lifts, drop floor, raised roof, lockdowns, driving equipment. Install, customize, repair. All mfgs.

B & R Mobility Services, Inc.
914 E. Skagway Ave.
Tampa, FL 33604
(813) 933-5452
Complete mobility equipment dealer. NMEDA Quality Assurance Program. Charter member with 5 star rating. Call for information.

Home Medical Equipment Co.
2137 Fowler St.
Ft. Myers, FL 33901
(800) 226-0404
New/Used Vans and equipment for the physically challenged. Full service and repair center. NMEDA member. Nationwide delivery.

Ocean Conversion & Mobility, Inc.
750 East Sample Road
Bldg. 8/#7
Pompano Beach, FL 30064
(305) 942-6033
Helping you meet your mobility needs. Total vehicle conversions. Certified Dealer/All Major Mobility Manuf. Customer assistance program. Member NMEDA.

Georgia

DuraMed Driving Systems, Inc.
1543 15th Street
Augusta, GA 30901
(800) 637-1378
Custom driving systems, whichr, scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Handicaps Mobility Systems, Inc.
5865-C Oakbrook Parkway
Norcross, GA 30093
(404) 662-5242
Full or mini-van adaptive conversions. Custom driving systems, authorized dealer for Braun, Crow River, Ricon, Mobile-Tech, EZ Lock, EMC Touch Pads, New & Used vans, rental vans NMEDA member.

Quail Country Customs
6922 Hardup Road
Albany, GA 31707
(912) 432-7258
Wheelchair lifts, scooter lifts, hand controls - Sales, Service. Braun, Crow River, Mobil Tech, Bruno, MPS, MPD. Member NMEDA.

Indiana

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Illinois

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Kentucky

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

NATIONAL MOBILITY EQUIPMENT DEALERS ASSOCIATION MEMBER

Look For This Symbol
It's Your Guarantee of Quality

It means your adaptive equipment dealer is a member of NMEDA – the National Mobility Equipment Dealers Association – and that he makes a special effort to assure customer Safety, Comfort, and Convenience!

- **NMEDA** members are professional factory-trained and certified.
- **NMEDA** dealers use only the proper tools and best materials, and employ certified technicians and welders, because the safety and welfare of their customers – and everyone on the road – is their first priority.
- A **NMEDA** customer knows the work on his vehicle has been professionally completed by a dedicated, caring and responsible dealer worthy of the customer's trust.

Call our toll-free National Hotline for the location of the **NMEDA** dealer nearest you:

1-800-833-0427

National Mobility Equipment Dealers Association

909 East Skagway Ave. • Tampa, FL 33607 • 1-813-932-8566

New Hampshire

Ride-Away Corp.
61 Wentworth Ave.
Londonderry, NH 03053
(603) 437-4444
The most complete line of new & used adaptive equipment for vehicles in New England. Lifts, ramps,wheelchair securements, new/used vans, trade-ins, financing available. 24 hours everyday. Service, healthcare professionals on staff.

New Jersey

Arcola Mobility
51 Kero Road
Carlstadt, NJ 07072
(201) 507-8500/(800)ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Causeway Ford Lincoln, Mercury, Jeep, Eagle, Inc.
Route 72 East
Manahawkin, NJ 08050
(800) 424-3875 Ext. 50
One-Stop mobility specializing in new-used conv. vans. We stock IMS, Minivans, Dist. of Major Equipment Products, IMS, EZ-Lock, EMC touch pad systems, Braun, Bruno & Ricon NMEDA member- NJ state and VA cert.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(2u1) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Barrier Free Systems, Inc.
165 Freeman's Bridge Road
Scotia, NY 12302
(518) 346-4169
We sell and install equipment in the aid of transportation for the physically challenged. For more information, give us a call!

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

New Era Transportation
810 Moe Drive
Akron, OH 44310
(800) NET-VANS
New and used adapted vans and a full line of adaptive equipment. Delivery and financing available. Call us for personalized service.

Tri-State Mobility
Canton, OH
(800) 343-3150
Toledo, OH
(800) 345-3150
One of the largest inventories of used handicapped vans. Nationwide delivery available on request. NMEDA member.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Mobility Sales & Service, Inc.
1128 Third Street
North Versailles, PA 15137
(412) 824-9091
Full size /Mini-van modifications, raised roofs/doors, lowered floors, wheelchair and scooter lifts, driving equipment.

South Carolina

DuraMed Driving Systems, Inc.
1543 15th Street
Augusta, GA 30901
(800) 637-1378
Custom driving systems, w/chr. scooter lifts, elevators, van conversions. IMS, Mobile Tech., Crow River, Ricon, EMC, MPD, EZ Lock. NMEDA & MED group.

Tennessee

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Marketplace

Camps

Camp Horizons
P.O. Box 323
South Windham, CT 06266
(203) 456-1032
Fifteen years of serving children & adults who are mentally handicapped. Summer & winter residential camp programs that challenge campers in a supportive and fun environment. Innovative social & recreational programs that build self-esteem & independence for each camper. ACA accredited.

Catalogs

Antoni Toys and Products
232 SE Oak st Suite 103
Portland, OR 97214
(800) 826-8664/(503) 233-1660
Assortment of colorful toys, one piece underwear, hand-made dolls, educational books, diapers and more! Call toll free for catalog.

M & C Company
P.O. Box 4107
Schenectady, NY 12304-4107
(518) 357-2808
Personalized children's books are fun, exciting and encourage reading. Great Gifts for all occasions. All time favorite titles. Free brochures.

Clothing

Adrian's Closet
P.O. Box 9506
Rancho Santa Fe, CA 92067
(800) 831-2577
Free catalog available now.

Cribs & Youth Beds

HARD Manufacturing Co.,Inc
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Dowd Rental & Sales
100 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been servicing the area since 1930. For personal service and quality equipment and further information call Dowd Rental & Sales, Inc.

BEAT THE HEAT!
- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927
Made in USA Pat. 5168893 *Providing Comfort to Those Who Want It!*

Rehabco®
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in childrens mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Oklahoma

Loyal LaPlante Supply Co.
6702 E. 11th St.
Tulsa, OK 74112
(918) 835-6381
Custom seating. Check Marc certified repairs. Authorized Check Marc Repair Center. We carry most products & advertised in this magazine.

New Hampshire

Advent Medical/Ride-Away
51 Wentworth Ave.
Londonderry, NH 03053
(603) 437-4444
Advent Medical specializes in all types of rehabilitation & mobility equipment for your child. Nurse & therapist on staff for any positioning issues. Dealers of all major brands of equipment. Skilled technicians, 24 hour everyday service. Huge list of references available.

New CARE, Inc.
1126 E. 2nd. Street
Casper WY 82601
(307) 577-0696
Full time specialist available in pediatric & adult fitting, seating & positioning for rehab equipment. Free home or office evaluations.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800)242-2460
Attends Youth Briefs fits children 35-75 lbs. $51.95/cs (96), Free Delivery. Also - Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Lift Aids

LIFT AIDS, INC.
2391 Pecan Ct.
Ft. Worth, TX 76117
(817) 834-3881
Metro (817) 429-7141
Mobility specialist for physically disabled. Largest wheelchair lift installer in Ft. Worth mid cities area. Authorized dealer/installer for Ricon, Crow River, Mobil Tech, Handicaps, Braun, Vantage Mini Vans. 5 Star dealer/member of NMEDA. Full repair & service since 1968.

Monitoring Systems

Care Electronics
5741 Araphoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home.Locate them up to ONE MILE away. FREE catalog.

Resources/Special Needs

LINCS-BBS C/O PHP,
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Seating & Positioning

Patient Transfer Systems
P.O. Box 421176
Los Angeles, CA 90042-1176
(800) 510-0051
Transfer Belt, padded four handled, makes transfers safer, easier & more effective. Greatly reduces risks of injury $35.95 each +(s&h).

For information on advertising in our Marketplace please call Barbara Nastro at 800-372-7368 or 201-680-4874

Books, Audio/Video & Educational Material

Books for Parents & Professionals

Turtle Books: provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to **Jason & Nordic Publishers,** P.O. Box 441 Hollidaysburg, PA 16648 Call (814) 696-2920 or FAX (814) 696-4250

Topics in developmental disabilities - respite care, learning through play, family-centered care, feeding/swallowing & more. Catalog for professionals & parents. **Media, Meyer Rehabilitation,** University of Nebraska Medical Center, 600 So. 42nd St., Omaha, NE 68198-5450 (800) 656-3937.

Special Camp Guide 1994. A directory of summer programs in the northeast for children with special needs. Checks or money orders for $9.00 payable to **Resources For Children with Special Needs,** 200 Park Ave. So., Suite 816, New York, NY 10003, (212) 677-4650.

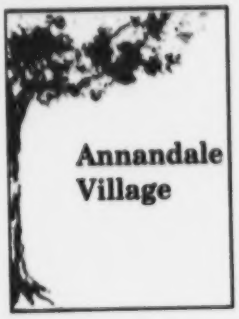
Free–The NEW Special Needs Project Book Catalog. The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. **Special Needs Project,** 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourette syndrome, Mental Retardation, Special Education and more. **Woodbine House** Contact: 5615 Fishers Lane, Rockville, MD 20852, (800)843-7323

Videotapes

Interax Video Sign Language Course. Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

For information on advertising Books, Audio/Video & Educational Materials please call Barbara Nastro at 800-372-7368 or 201-680-4874



"THEIR COMMUNITY ... WITH OUR HELP" Private, nonprofit community for adults with developmental disabilities. Residential and day/evening programs and services.
- Paid Job Training
- Arts Activities.
- Therapeutic recreation.
- Case management.
- 125-acre wooded environment.

Annandale at Suwanee, Inc.
3500 Annandale Lane, Box 7
Suwanee, GA 30174
(404) 945-8381

"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

33rd Year

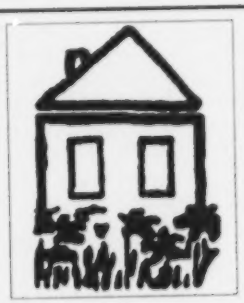
A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled; ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

SHEVET ACHIM in conjunction with YACHAD/NCSY is a new & exciting summer program in an Israeli Kibbutz. This four week program is designed specifically for high functioning Jewish young adults with developmental disabilities. Located in Kibbutz Ein Zurim, central Israel. Sabbath and Kosher dietary laws observed.

SHEVET ACHIM
63-67 108th Street
Forest Hills, New York 11375
(718) 997-1111 New York
(213) 651-5122 Los Angeles
(312) 764-4019 Chicago



RESPITE SERVICES provides short term residential care for children, adolescents and adults with disabilities. Respite Services gives a weekend break, vacation or help in times of illness or other crisis. Summer camp sessions are also available. Family style care and welcome in a country setting.

Contact: John & Pat Ryan
Respite Services
RRI Box 458
S. Gibson, PA 18842
(717) 756-2750
(717) 756-2870 Fax

A PLACE TO CALL HOME
Special Force Family Ministries operates superior quality residential programs for adults with mental retardation in private homes near Minneapolis, MN and Springfield, MO. Residents become members of individual families where Christian values are affirmed. Community involvement. Recreational opportunities. Affordable rates. Established 1973. Call for details.

Contact:
Special Force Family Ministries
P.O. Box 47, Waconia, MN 55387
(612) 442-4441

EXCEPTIONAL PARENT MAGAZINE IS NOW PUBLISHING MONTHLY!

Only $24.00 for 12 issues

To order your subscription call:

1-800-247-8080

($30.00 Canadian; $33.00 Foreign)

TENNESSEE

TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available.

Contact: Ron & Cammie Eydt
Tall Pine Camp
114 Tall Pine Circle
Tellico Plains, TN 37385
(615)261-2329/(615) 261-2138

Our Civil War Over Residential Care

by Richard Haddad

Erin Haddad, eighteen years old.

For years, I had been aware of the efforts of some parents and advocates to close all institutions for people with mental retardation by moving their residents into group homes in the community. While waiting at the hospital one day for my daughter, Erin, to come out of major surgery, I was struck by something very odd about this movement.

In the weeks before Erin's surgery, my wife Valorie and I had received tremendous support from friends and acquaintances. We had been forced to make a difficult decision. Without a spinal operation, Erin could face painful, even life-threatening organ damage in the years to come. On the other hand, the operation itself was risky—there was a 20 percent chance she wouldn't make it through surgery and recovery.

After much consultation and deliberation, we decided to go ahead with the surgery. No one questioned our decision or, more importantly, that it was ours to make. Everyone seemed to share in our anxiety as the day of the operation—coincidentally, Erin's eighteenth birthday—approached.

Why, I wondered, weren't we getting this kind of support from the disability community on our decision about where Erin would be living by the end of the year if she survived the surgery?

Warring camps

Erin has cerebral palsy. She can't walk, she's blind, and her brain has developed only to the level of a one-year-old. She wears diapers and needs to be fed, bathed, dress74ed and groomed. Valorie had been providing her with this care for the last 18 years and needed relief. It was time for Erin to leave home.

As I learned, we parents of children with mental retardation are divided into warring camps on the issue of residential care. One camp, composed mostly of people with higher functioning kids, thinks it is most important that their children are included in all aspects of family and community life. They promote placement in a community living arrangement (CLA).

The objectives of CLA advocates extend far beyond securing the best living environment for their own children. Their mission is to change the attitude of society as a whole, so that their children and others like them can lead as "normal" a life as possible. In their view, institutions symbolize unenlightened public policy.

I remember listening silently at one organization meeting as a pro-community parent explained the importance of including our children in all aspects of family life. While he talked, all I could think about was the indigestion we had experienced when we tried bringing Erin with us to a restaurant. And I'll never forget my disbelief on hearing an officer of that group speculate seriously with me about Erin's vocational potential, when she had never even met her.

The folks in the other camp, usually those with the lowest functioning

Erin Haddad (center) surrounded by (from left) sister Ashleigh, mom Valorie, and brother Jonathan.

children, put a higher value on the care itself, and favor centralized care in a traditional setting such as a state residential center (SRC). Their children are those with severe or profound retardation, often accompanied by complicated medical conditions or physical disabilities. They have little or no concept of community, no vocational potential and no chance of living anything remotely resembling a "normal life."

These parents feel that a community residence would not provide their children with the necessary level of care, attention and protection. They deeply resent the anti-institutional bias of the pro-community activists, and lash out in a similar fashion, finding fault wherever they can with group-home living.

One official, at an SRC parent association meeting, related stories of people in group homes becoming injured and seriously ill due to neglect. In a later conversation, she implied that abuse was not uncommon in community residences, and advised that my daughter would be much safer in an institutional setting.

> *"The combatants have allowed ideology to bury their compassion—they are ignoring the shared understanding that comes from common experiences of raising children with disabilities."*

There is much about this infighting that should bother all parents and advocates. The combatants have allowed ideology to bury their compassion—they are ignoring the shared understanding that comes from common experiences of raising children with disabilities. They have stopped respecting each other. But they are also failing to provide needed information and support to parents for whom the best choice is not obvious.

An unlikely ally

It was ironic. We did not find the critical help and support we needed to make the decision about where Erin would live from other parents or from disability advocates. Instead, we found an unlikely ally in our search for answers—the much-maligned State Developmental Disabilities Administration.

Staff of the Developmental Disabilities Administration arranged for us to tour residential facilities in different areas so we could see what was available. We visited several group homes and toured the day activity centers run by each. We also visited an SRC to see for ourselves how institutional care compared with

that provided in the community-based residences.

What we saw on these tours surprised us. We found the SRC to be clean, quiet and well-staffed with courteous people. Many of the residents had greater medical needs than Erin. All appeared to be receiving good care.

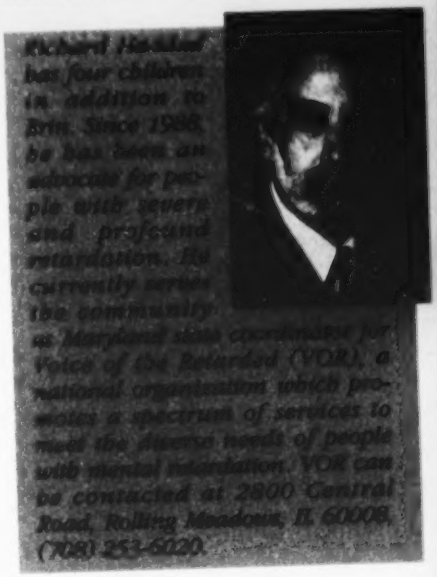
We especially liked one community facility because of the tenderness which characterized the care administered. We toured other communtiy care facilities, however, where administrators seemed more concerned with the progressiveness of their programs than the quality of their care. And we immediately ruled out one CLA with a large day activity center that reminded us of a factory.

Respect for the choices of others

After careful consideration, Valorie and I decided that we wanted Erin to live in the group home with the caretakers whose tenderness had so impressed us. We know that it won't matter to Erin where she gets that care; but as long as she remains relatively healthy, her family is more comfortable with her living in an environment like the one in which she grew up. In the end, it was that simple.

Meanwhile, we are glad for having learned about the quality of our state's institutional system. We will always be grateful for the professionalism of the state personnel who made sure we had enough information to make our decision, then stood back and let us decide.

I don't know how it was that we parents and advocates let our common concern for the well-being of our children turn into a civil war on this issue. For the sake of our children, however, we need to become a united community again. For the sake of good public policy, we need to recognize that there are important differences among our children which may require a different type and level of care. Above all, we need to grant other parents proper motives and good reasons for making the choices they do. The burden we bear is heavy enough without the weight of judgments of others. ■



Richard Haskell has four children in addition to Erin. Since 1988, he has been an advocate for people with severe and profound retardation. He currently serves the community as Maryland state coordinator for Voice of the Retarded (VOR), a national organization which promotes a spectrum of services to meet the diverse needs of people with mental retardation. VOR can be contacted at 2800 Central Road, Rolling Meadows, IL 60008, (708) 253-6020.

Camp Loyaltown AHRC

Camp Loyaltown provides a safe, fun-filled, enthusiastic & stimulating summer recreational vacation for mildly & moderately developmentally disabled children and young adults. Nestled in the Catskill Mts. at Hunter, NY, we offer classes in music, dance, drama, ceramics, wood working, sewing, cooking, swimming, athletics and team sports, recreation, crafts and nature.

Contact: Paul Cullen
Camp Loyaltown AHRC
189 Wheatley Rd.
Brookville, NY 11545
(516) 626-1007 x444

LEE MAR
SUMMER CAMP AND SCHOOL

SERVING MILDLY RETARDED & DEVELOPMENTALLY DELAYED
42nd year of camp leadership in beautiful Poconoc. Co-ed 5-18. Balanced program geared to individual needs of campers. Academics, speech & language therapy, social, motor & perceptual training, plus innovative recreational & athletic activities. For free brochure:

Contact: Lee Morone
Camp Lee Mar, 360 E. 72nd St.
Suite A-711, New York, NY 10021
1 800-8-LEEMAR

TLC THE LEARNING CLINIC, INC. a private, non-profit corporation

THE LEARNING CLINIC
Country School and Residence enrolling children of all ages in a year-round program of specialized treatment for attention deficit and learning disability.
- small, selective and personal
- rural setting, pastures and animals
- tutorials in all subjects
- young apprentice program
- wilderness trips

The Learning Clinic, Inc.
P.O. Box 324
Brooklyn, CT 06234
(203) 928-5274
(203) 774-7471

CAMP SKY RANCH

REAL CAMPING FOR THE MENTALLY HANDICAPPED.
Activities carefully supervised-swimming, boating, riding, crafts. These are just some of the activities campers will enjoy. Founded in 1948 in the mountains of North Carolina.

Contact: Dan Norman or Betty Sharp
Camp Sky Ranch
Rte. 1, Box 540
Blowing Rock, NC 28605
(704) 264-8600

CHARLES C THOMAS • PUBLISHER

☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 276 pp., 13 il., 1 table.

The purpose of this handbook is to help children who learn differently and who have been failing or underachieving in school. It does this by giving enough information for an adult with no previous teaching experience to design and implement an effective remedial program. Most parents feel guilty when their children do not do well in school, and the first section is designed to help parents make realistic changes in the physical and emotional environment at home and at school. The second section gives simple objective tests that show what a child knows and what he needs to learn. It evaluates the maturity of skills in memory, visual-perception and auditory-perception, as well as skills in reading, spelling, phonics, and math. The final section shows how to use test findings to determine which subjects should be taught and specific techniques for teaching them. The concept that children learn better when they feel successful is emphasized. No special knowledge on the part of the reader is needed to understand and use this information.

☐ Camerer, M. C. Gore—**A PARENT'S GUIDE TO COPING WITH ADOLESCENT FRIENDSHIPS: The Three Musketeer Phenomenon.** '94, 186 pp. (7 × 10), 1 il.

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 314 pp. (6¼ × 9¼), 100 il., 14 tables.

☐ Humphrey, James H.—**SPORTS FOR CHILDREN: A Guide for Adults.** '94, 218 pp. (7 × 10), 5 il., $34.75

☐ Kass, Corrine E. & Cleborne D. Maddux—**A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice.** '93, 222 pp. (7 × 10), 3 il., $45.75.

☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $50.50.

☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, $52.75.

☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), $35.75.

☐ Oppenheim, Rosalind C.—**EFFECTIVE TEACHING METHODS FOR AUTISTIC CHILDREN. (2nd Ptg.)** '77, 124 pp., $26.00.

☐ Giordano, Gerald—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.

This book focuses on children who are failing to learn mathematics and typical classroom programs, using routine instruction and routine materials. Even children with disabilities who have been mainstreamed into regular education classrooms can be most successful if their teachers are sensitive to subtle variations in their learning. This book differentiates the social, emotional, cognitive, and academic factors that contribute to learning remedial mathematics. The text highlights multiple opportunities for evaluating mathematical skills formally and informally, as well as procedures for strengthening academic evaluation. While diagnosis is discussed extensively, the clear emphasis is on corrective strategies that illustrate a problem-solving approach to learning. Special education teachers enrolled in a methods course that focuses on mathematics instruction will not want to be without this book. In-service teachers will be drawn to it as a professional development resource.

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.

☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.

☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¼ × 9¼), 113 il., 19 tables, $59.75.

☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 x 10), 21 il., $37.75.

☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.

☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.

☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 × 10), $47.75.

☐ Durán, Elva—**TEACHING THE MODERATELY AND SEVERELY HANDICAPPED STUDENT AND AUTISTIC ADOLESCENT: With Particular Attention to Bilingual Special Education.** '88, 250 pp. (7 × 10), 5 il., 3 tables, $45.50.

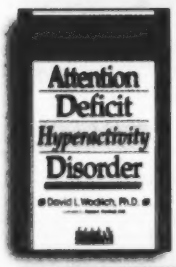
Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice Circle #10

2600 South First Street Springfield • Illinois • 62794-9265

EXCEPTIONAL PARENT *Library*

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER



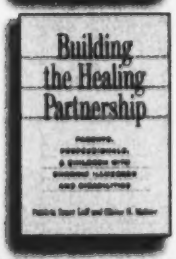
ATTENTION DEFICIT HYPERACTIVITY DISORDER: ***What Every Parent Wants to Know***
D. WODRICH
Prepares parents for at home and at school, empowers and reaffirms parents of their role.
PB070AD **$19.95**

AUTISM

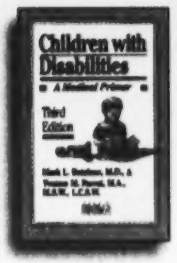
REACHING THE AUTISTIC CHILD
MARTIN KOZLOFF
Focuses on a parent training program that shows how to improve the environment of the autistic child.
BL0630D **$14.95**

DISABILITY, GENERAL

BROTHERS AND SISTERS
A Special Part of Exceptional Families
THOMAS H. PEWELL
Includes 30 parental strategies and 20 sibling strategies suggested by a panel of siblings.
PB072OD **$23.00**



BUILDING THE HEALING PARTNERSHIP: ***Parents, Professionals & Children with Chronic Illnesses and Disabilities***
PATRICIA T. LEFF
BL057OD **cloth: $34.95**
paperback: $24.95

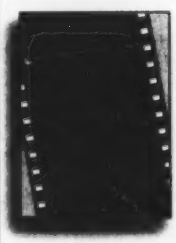


CHILDREN WITH DISABILITIES: ***A Medical Primer***
M. BATSHAW
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.
PB071OD **$29.00**

DECIPHERING THE SYSTEM: ***A Guide for Families of Young Children with Disabilities***
PAULA J. BECKMAN
Informs parents of children (0–5) of their rights.
BL058OD **$21.95**

DISABLED, FEMALE, AND PROUD! ***Stories of Ten Women with Disabilities***
HARILYN ROUSSO
Offers young women with disabilities empowering role models.
GW003EP **$12.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services.***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**

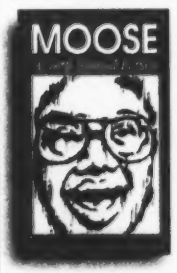


THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals
EP001EP **$14.95**

LIVING IN A STATE OF STUCK: ***How Adaptive Technologies Affect the Lives of People with Disabilities***
MARCIA J. SCHERER
BL064OD **$32.95**

MAKING CHANGES: ***Family Voices on Living with Disabilities***
JAN A. SPIEGLE
Shares self-reports and visions on how families and professionals make changes.
BL061OD **$19.95**



MOOSE: ***A Very Special Person***
W. SCOTT MACDONALD
Moose teaches us that each of us is different and that we have our own unique capacity for loving, sharing, enjoying and learning.
BL065OD **$10.95**

PERSPECTIVES ON A PARENT MOVEMENT: ***The Revolt of Parents of Children with Intellectual Limitations***
ROSEMARY DYBWAD
Captures the author's truly innovative wisdom and pioneering work.
BL059OD **$17.95**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

PLANNING FOR THE FUTURE: ***Providing a Meaningful Life for a Child with a Disability after Your Death***
MARK RUSSELL
AP024OD **$24.95**

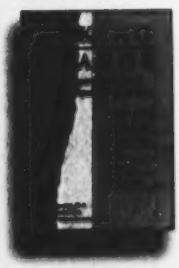
THIRD PARTY BILLING FOR SPECIAL EDUCATION: ***Panacea or Mirage?***
JOY J. ROGERS
The use of third party billing to cope with escalating special education costs, especially those not directly educational.
BL066OD **$27.95**

WORKING TOGETHER: ***Workplace Culture, Supported Employment and Persons with Disabilities***
DAVID HAGNER
Assisting individuals to achieve meaningful careers.
BL060OD **$24.95**

DISABILITY, PHYSICAL

COPING WITH CEREBRAL PALSY: ***Answers to Questions Parents Often Ask***
JAY SCHLIECHKOM
Provides answers to more than 300 questions that have been carefully researched.
PE037PD **$24.00**

NO TIME FOR JELLO ***One Family's Experience with the Doman-Delacato Patterning Program.***
BERNEEN BRATT
One family's experience with patterning for a child with Cerebral Palsy.
BL062CP **$17.95**

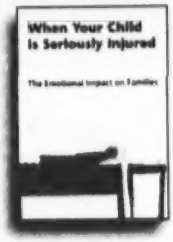


TAKING CHARGE: ***Teenagers Talk About Life & Physical Disabilities***
EDITED BY K.H. KRIEGSMAN
Explore the wide range of issues that teenagers with physical disabilities face as they approach adulthood.
WB013PD **$14.95**

INJURY

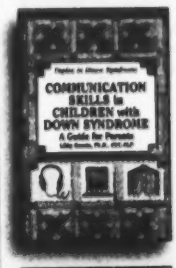
INJURED MIND, SHATTERED DREAMS: ***Brian's Survival from a Severe Head Injury***
JANET MILLER RIFE
Recovery and victory a family can achieve through caring.
BL067OD **$17.95**

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$5.00**



WHEN YOUR CHILD IS SERIOUSLY INJURED: ***The Emotional Impact on Families***
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$2.00**

MENTAL RETARDATION



COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME ***A Guide for Parents***
LIBBY KUMIN
Parents learn how communication skills progress from infancy through the early teenage years.
WB031DS **$14.95**

COUNT US IN ***Growing Up with Down Syndrome***
J. KINGSLEY & M. LEVITZ
The authors share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship.
HB073DS **$9.95**

DEATH AND DYING: ***A Guide to Serving Adults with Mental Retardation***
M. HOWELL
Explores psychological, medical, spiritual and legal matters.
GW004EP **$7.95**

DOWN SYNDROME: ***An Introduction***
CLIFF CUNNINGHAM
A comprehensive and well organized work for parents of babies and children. Answers to countless questions.
BL068DS **$12.95**

ETHICAL DILEMMAS IN CAREGIVING: ***A Guide for Staff Serving Adults with Mental Retardation***
M. HOWELL
Examines cases where there are clear-cut dilemmas about the "best" course of action.
GW069MR **$8.95**

SERVING THE UNDERSERVED: ***A Handbook for Caregivers***
EDITED BY D. GAVIN
All the areas of experience affecting the lives of adults who are mentally retarded and old.
GW011MR **$29.95**

Mail to: **Exceptional Parent,** Dept. EP9403, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

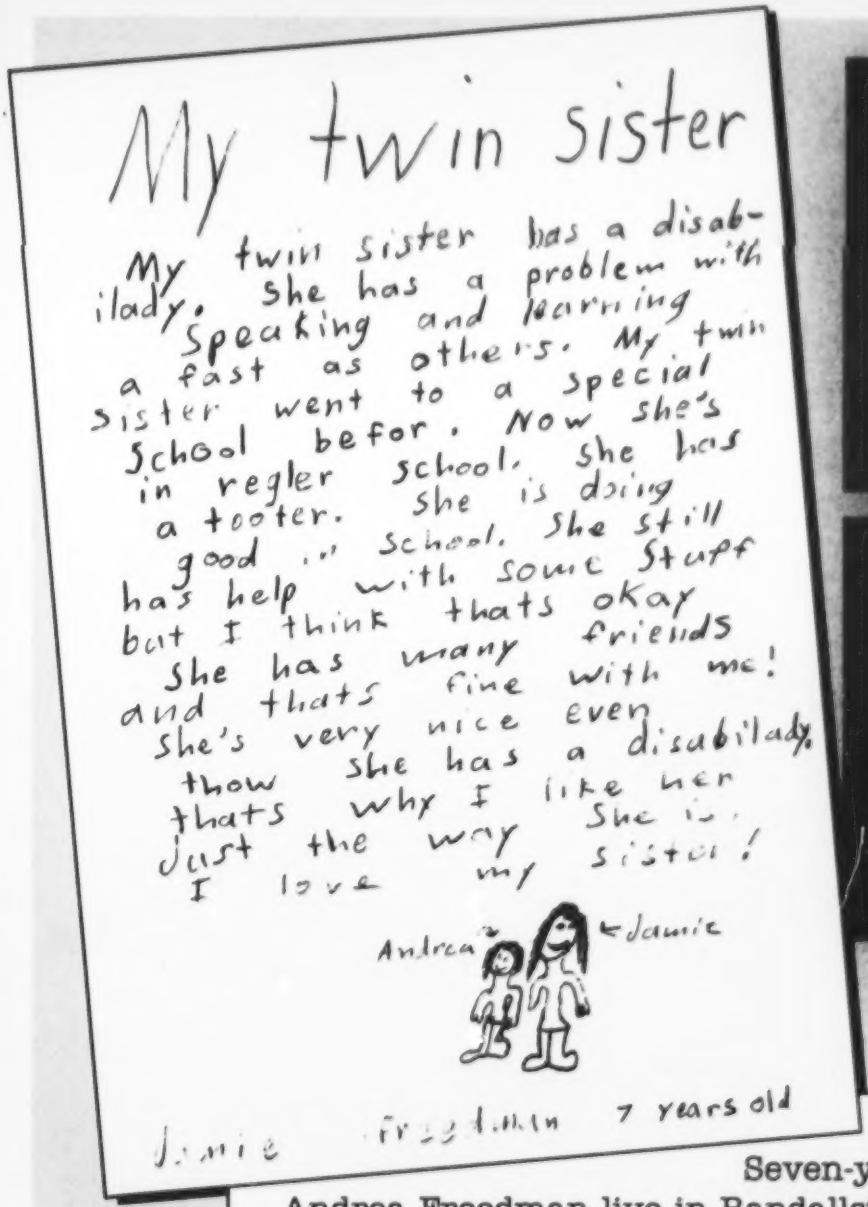
City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my:

❑ Visa ❑ Mastercard Exp. Date ____/____ Signature _____

CHILDRENS' PAGE


My twin sister

My twin sister has a disabilady. She has a problem with Speaking and learning a fast as others. My twin sister went to a special School befor. Now she's in regler school. She has a tooter. She is doing good in school. She still has help with some Stuff but I think thats okay She has many frieiids and thats fine with me! She's very nice even thow she has a disabilady thats why I like her just the way She is. I love my sister!

Andrea ←Jamie

Jamie Freedman 7 years old

Jamie and Andrea Freedman

Seven-year-old Jamie and Andrea Freedman live in Randallstown, MD with their parents, Mona and Jay Freedman. Andrea has language and learning disabilities. Both girls attend Randallstown Elementary School where Jamie is in second grade, and Andrea is in first grade. Mona, coordinator of the Family Support Network within Maryland's Infants and Toddlers Part H Program, wrote about her experiences with early intervention in "Perspectives on Early Intervention" (February 1994).

Confidence, Independence, Success...

The Crotched Mountain Rehabilitation Center and Preparatory School offers innovative academic, therapeutic, residential, and medical services designed to maximize the educational potential of physically and developmentally challenged children and young adults with:

- Head Injury
- Cerebral Palsy
- Spina Bifida
- Autism
- Down's Syndrome
- Developmental, Behavioral, Emotional and Neurological Disorders
- Fetal Substance Exposure

The CMRC program includes:

- Fully Accredited Preparatory School Curriculum
- Modern Residential Group Homes
- Licensed Skilled Nursing Facility
- Accessible, State-of-the-Art Library
- Total Communications Center
- Fully Adaptive and Accessible Sports Facility
- Comprehensive Transition Services

For more information on these services or those of our subsidiaries, please contact our Admissions Officer, Debra Flanders at (603) 547-3311, ext. 235.

CROTCHED MOUNTAIN

A subsidiary of the Crotched Mountain Foundation
1 VERNEY DRIVE, GREENFIELD, NH 03047, (603) 547-3311

Circle #17

Gone Fishin'

Fishing Has No Boundaries is a non-profit organization which promotes access to the outdoors for individuals with disabilities through annual fishing events. The organization also works with various governmental agencies to enhance accessibility to lakes and rivers.

Event participants are welcomed regardless of age, sex or disability. By working with volunteers at the events, participants build confidence and find that there are many ways to experience the great outdoors. Events offer a unique experience to individuals who otherwise may not have such an opportunity.

The next event is scheduled for May 20–22, 1994 in Hayward, WI. June events will be held in Eagle River, WI, Thermopolis, WY, Pierre, SD, and Bemidji, MN.

For more information, contact Fishing Has No Boundaries, P.O. Box 175, Hayward, WI 54843, (800) 243-3462 or (715) 634-3185.

Senate Adopts Dole Amendment to GOALS 2000 Bill

The Senate has adopted Senator Robert Dole's (R–Kansas) amendment to the GOALS 2000: Education America Act Bill. Dole's amendment calls for a study of how well children with disabilities are served by the bill.

The GOALS 2000 Bill provides states and localities with technical and financial support for education reform initiatives. The bill authorizes $400 million in federal grants to promote improved teacher training, increase parental involvement, and use federal funds flexibly.

In a statement made following Senate acceptance of his amendment, Senator Dole stated, "I am concerned that students with disabilities will miss the bus when it comes to school reform. Although I do not intend or expect this study to rewrite GOALS 2000, we must be sure that goals, standards and assessments work for students with disabilities, not against them by promoting their exclusion.

"I know that the bill contains many references to students with disabilities, and I commend the Committee on Labor and Human Resources for its strong report language in this regard. But neither bill or report language can make up in one fell swoop for a decade of neglect."

New Support Groups

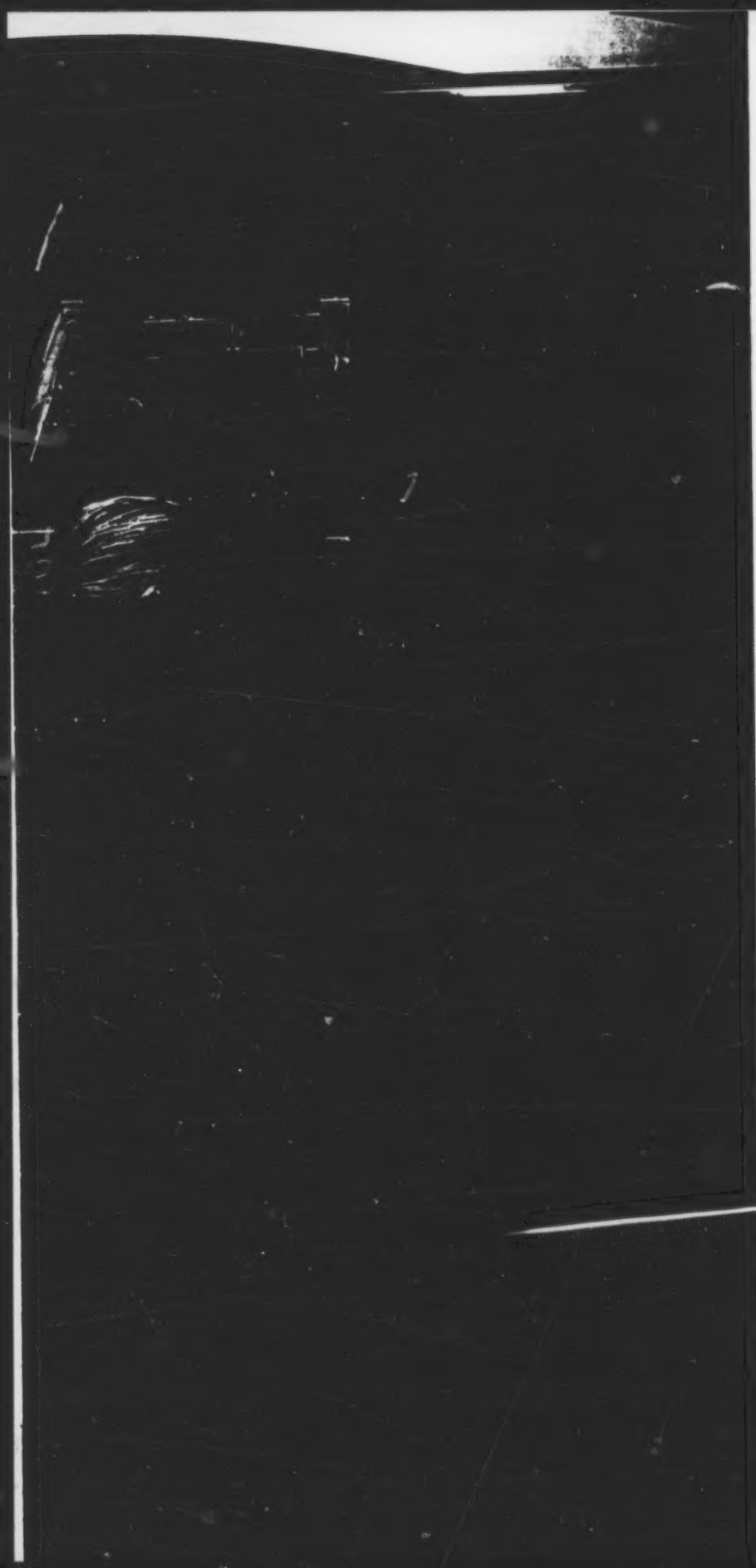
- A new support group is being formed for those interested in *Stickler Syndrome*. Contact Jennifer Purvis, 2123 Royal Oaks, Dallas, TX 75253, (214) 286-5638.
- A support group has been formed for parents of children with *Chromosome 6 disorders*. For more information contact Spotlight 6, c/o Valerie Wiggins, 2617 Red Toad Road, Rising Sun, MD 21911.
- *Cockayne Syndrome (CS)*, also known as *Cachetic dwarfism*, is characterized by failure to thrive, photosensitivity, retinopathy and/or cataracts, hearing loss and microcephaly. Facial characteristics include a pinched face, projecting jaw, malformed ears, beaked nose and sunken eyes. Not all children with CS have every trait. For more information, contact Share & Care, c/o Teresa Wall, P.O. Box 552, Stanleytown, VA 24168, (703) 629-2369 or (800) 484-7601 security code 2468.

Publications

- *Hope Through Research: Cerebral Palsy* is a new brochure published by the National Institute of Neurological Disorders and Stroke (NINDS). Free copies can be obtained by contacting NINDS at 9000 Rockville Pike, Bldg 31, Room 8A-16, Bethesda, MD 20892, (800) 352-9424.
- *Parent Support Networks, A Workbook for Creating Successful Community Support Groups* provides information on starting and running successful support groups. The workbook may be obtained at no charge from the Maine Parent Federation, P.O. Box 2067, Augusta, ME 04338-2067, (207) 582-2504.
- *Resources the Disabled Can Use to Acquire and Fund Computers* is a free publication that includes sources for grants, programs, services and technology-related assistance. For a copy, send a long, self-addressed, stamped envelope to "Free Computer Report," Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666.

Inclusion Awards

Each September, we honor education programs via our Annual Inclusion Awards. Now is the time to nominate programs that provide fine educational and social opportunities for children with disabilities, help peers welcome children with disabilities and invite active parent participation. Please mail your nominations (500 words or less, plus pictures whenever possible) to: Inclusion Awards, *Exceptional Parent*, 209 Harvard St., Suite 303, Brookline, MA 02146.



HALF A LIFT IS *STILL* BETTER THAN WHOLE.

With maximum passenger seat maneuverability, a new easy off/on ground hugging platform, plus reliable all-electric operation.

The Crow River Industries VANGATER™ fold-in-half lift is a timeless classic. When folded it offers half a doorway of usable space for easy loading/unloading, more usable interior space, a clearer side view, and allows the front passenger seat to be almost fully reclined for maximum comfort. But we can't seem to stop trying to improve on perfection.

All-electric reliability.

The enclosed non-hydraulic, all-electric operating mechanism is cleaner and quieter than hydraulic lifts, especially in extreme temperatures. (There's also no leakage or unpleasant odor.) And our new auxiliary electric override provides emergency electrical lift power—not to mention peace of mind—when you need it most.

A flatter platform.

We've made getting on and off the VANGATER™ easier than ever with a new flatter platform that sacrifices nothing in ruggedness and reliability. And you'll find the improved side entry option and exit access great in tight parking situations!

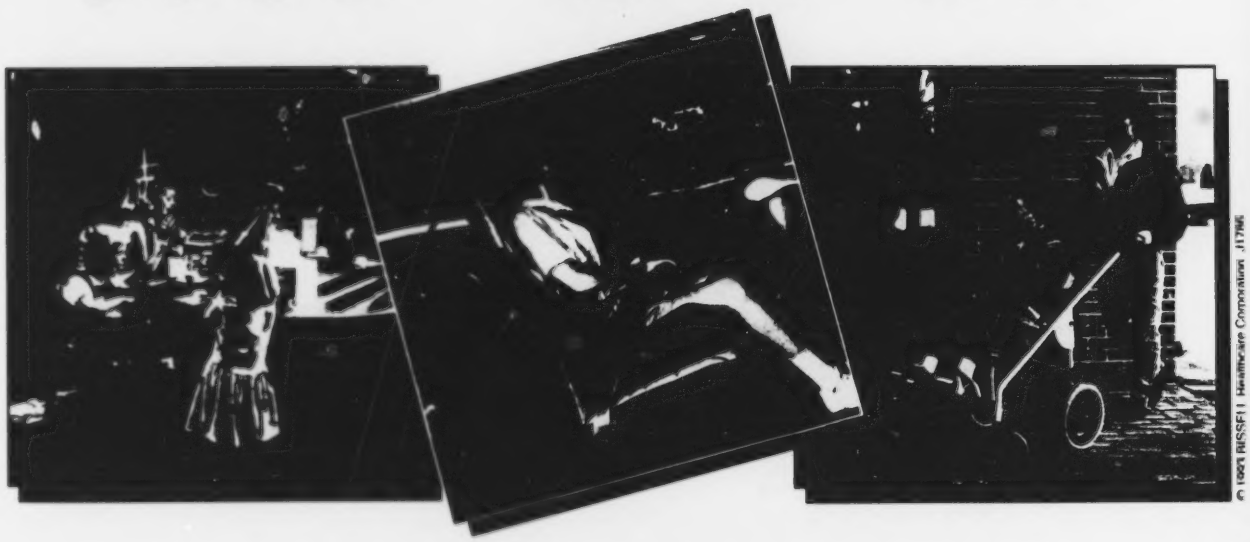
RAPID RESPONSE LINE:
For more information and the name of your closest dealer call *today*:
1-800-488-7688

Circle #14

CROW RIVER™
Industries Incorporated

14800 28th Avenue North
Minneapolis, MN 55447 (U.S.A.)
(In Minnesota, 612-559-1680)

Rover *all Over*



© 1992 RISSELL Healthcare Corporation J1796

It's...The Carrie Rover from Tumble Forms —offering everything you want in a seat and stroller

Now your special needs child can easily roll from one activity to another. The Carrie Rover can take your child from the home to the car, to strolling on outdoor terrain.

Your child will have freedom and mobility without sacrificing therapeutic support. The anti-thrust seat stabilizes the pelvis while the seat back articulates 20° to accommodate abnormal trunk tone. The Carrie Seat removes for use as a positioning chair and the streamlined roller base folds small enough to fit easily into the trunk of your car.

Lightweight and versatile, Carrie Rover comes in four sizes, pre-school, elementary, junior and **small adult**.

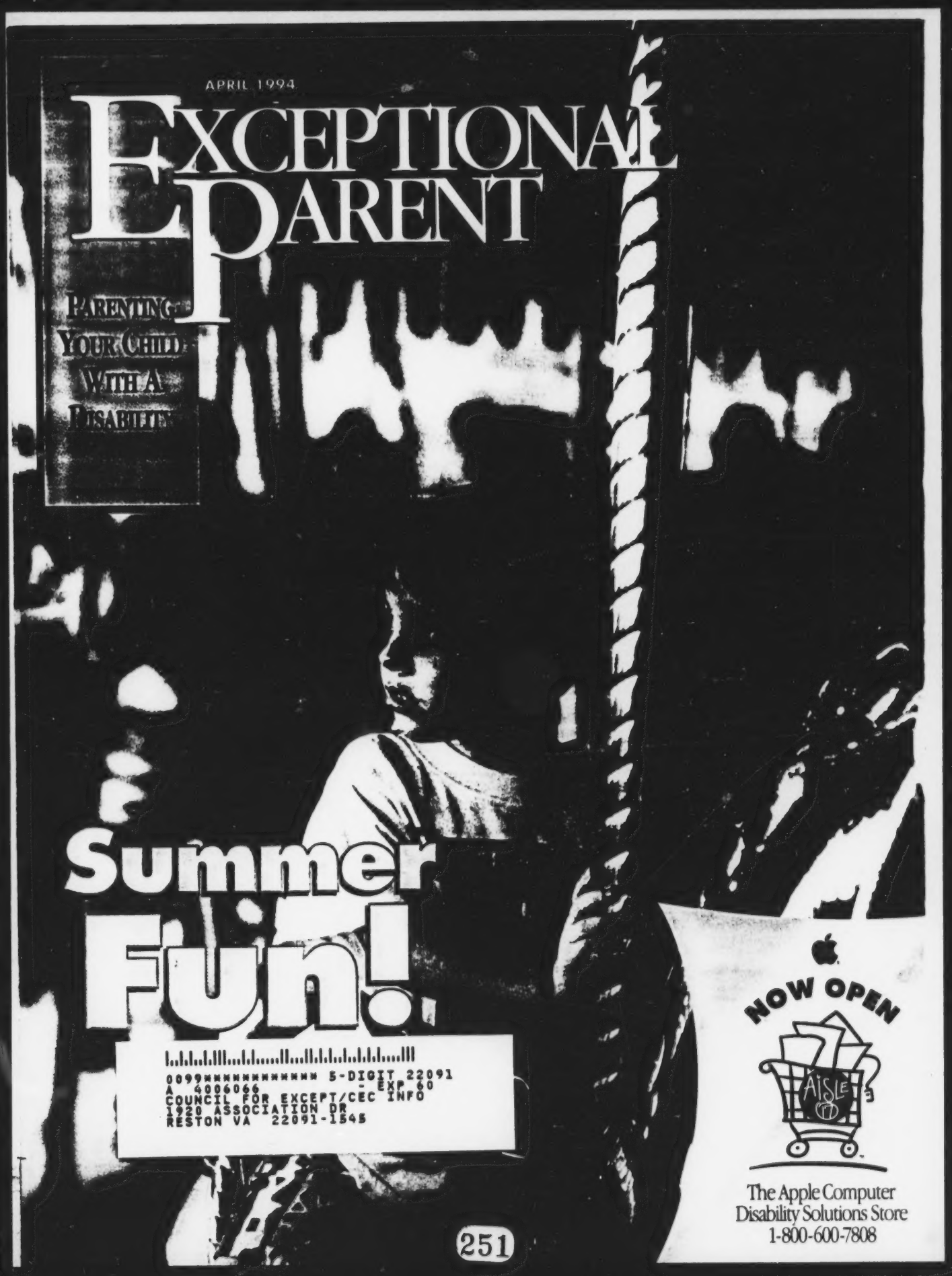
The Carrie Seat has been dynamically crash-tested for use in the car. It complies with F.M. V.S.S. 213. Carrie Rover has been dynamically crash-tested for use on school buses with standard forward facing tie down systems.

Carrie Rover goes anywhere your child wants to...indoors or outdoors.

The Carrie Rover—only from Tumble Forms. For more information call 1-800-631-7277 or write to J.A. Preston, P.O. Box 89, Jackson, MI 49204-0089.

Tumble Forms®
by Preston.

Circle #7


APRIL 1994
EXCEPTIONAL PARENT
PARENTING YOUR CHILD WITH A DISABILITY
Summer Fun!
0099NNNNNNNNNNNN 5-DIGIT 22091
A 4006066 EXP 60
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1545
NOW OPEN
AISLE
The Apple Computer
Disability Solutions Store
1-800-600-7808
251

One number is making long distance relay calls easy from anywhere in America.

AT&T Long Distance Relay Service

You don't need different 800 numbers for long distance relay calls from different states any longer. All you need is AT&T Long Distance Relay Service. With one number for all your long distance calls.

1 800 855-2880 (TT/TTY)
1 800 855-2881 (VOICE)
1 800 855-2882 (ASCII)
1 800 855-2883 (TELEBRAILLE)

One number from anywhere in the United States. One number to everywhere you call long distance on relay. AT&T Telecommunications Relay Services and Operator Services for the Deaf. *We're dedicated to making your phone calls easy.*

AT&T

Circle #170

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

APRIL 1994
VOL. 24, ISSUE 4

PAGE 22

COVER:

Four-year-old Peter Brooks enjoys a ride on the merry-go-round. His parents' story about the family's vacation at Disney World begins on page 25.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER:** Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year. $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

SUMMER FUN

All in the Family by Kate Divine McAnaney 22
Family vacations are for every member of the family!

An Exceptional Visit to Disney by David and Susan Brooks 25
Careful planning helps Peter's family enjoy a visit to Disney World.

Travel Resources 28
Accessibility information resources for vacationers.

FEATURES

Sense of Humor Required by Lynn Kimball Fay 32
Josh's parents learn to laugh.

GUEST EDITORIAL
Inclusion: Rhetoric and Reality by Edwin W. Martin 39
How well does inclusion work?

Listening to Learn by Elizabeth C. Mayer 46
A tape recorder helps Eliot with his homework.

Cycling 52
Adaptive equipment can make cycling accessible.

DEPARTMENTS

Editor's Desk 2

Letters 4

Search & Respond 8

Role Models: JASON KINGSLEY AND MITCHELL LEVITZ 17
Young authors challenge stereotypes and misconceptions

Fathers' Voices: DREAMS by John Cox 44
A father's dreams for his daughter's future

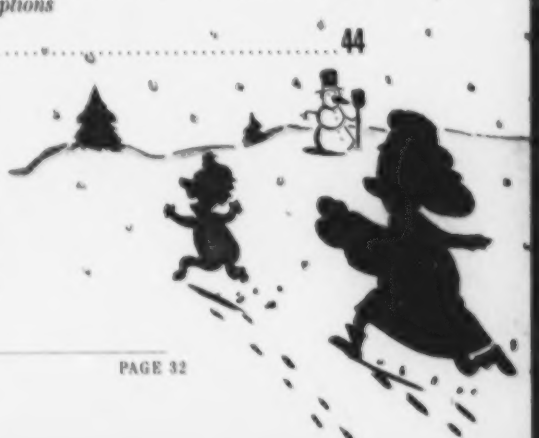
What's Happening 51

New Products 54

Informational Forum: Networking 55

Directory of Advertisers 58

Children's Page 68



PAGE 32

EDITOR'S DESK

After this hard winter, we are all looking forward to summer fun. Two articles, "All in the Family" by Kate Divine McAnaney and "An Exceptional Visit to Disney" by David and Susan Brooks recount the vacation experiences of two families. Our directory of "Travel Resources" also can help families make plans.

Many parents will find valuable ideas for coping with homework in "Listening to Learn" by Elizabeth C. Mayer. Mayer's story is a wonderful example of the creativity of parents in finding ways to help children learn.

STANLEY KLEIN, PH.D.

Devoted readers tell us that they appreciate and identify with articles written by other parents of children with disabilities. At the same time, many have commented on the underlying sadness of many of these stories. "Sense of Humor Required," by Lynn Kimball Fay, is a story that will remind us of some of the lighter moments of our everyday life with children. We hope this article will encourage other readers to share humorous moments with us.

The debate on health care reform continues. We join with the National Parent Network on Disabilities (see Networking) in urging readers to continue to write to our leaders in Washington.

Role Models

We have received many favorable comments about our new regular department, "Role Models." This month, we feature Jason Kingsley and Mitchell Levitz, authors of *Count Us In: Growing Up with Down Syndrome.* We caught up with Jason and Mitchell at a Boston television station where they had just completed another interview as part of their book tour. These young men speak with authority for themselves and for people with disabilities as they challenge stereotypes and misconceptions about people with Down syndrome—some of ours were challenged by this interview.

Inclusion

Although inclusion is appealing as an educational concept, its actual achievements have been the focus of considerable media attention and debate. I invited Edwin Martin, a long-time member of our Editorial Advisory Board, to write a guest editorial on this topic. Eminently qualified to speak out on this important issue, Dr. Martin served from 1966 until 1981—under four Presidents—as the leading government advocate and spokesperson for children with disabilities and their families.

New Products Page

Beginning with this issue, *Exceptional Parent* will include a monthly "New Products" department prepared by ABLEDATA, a respected, independent organization. Our goal is to present a wide range of innovative products for children with disabilities.

Welcome, Aisle 17!

Since 1985, when Apple Computer established its Worldwide Disabilities Solutions Group under the direction of Alan J. Brightman, Ph.D., Apple has been a leader in technology accessibility for children and adults with disabilities. In 1987, Apple collaborated with the Disabled Children's Computer Group of Berkeley, California to create the Foundation for Technology Access (FTA) and establish the Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers (see "ATA Directory," January 1994). Now, with input from children and adults with disabilities, parents and professionals, Apple has created "Aisle 17," a mail-order disability solutions store dedicated to computing without boundaries. "Aisle 17" is the first one-stop source for bundled computer solutions designed specifically for children and adults with disabilities.

Photos and drawings

Thanks to the many readers who have already sent wonderful snapshots and children's art. We are having a hard time choosing photos and drawings to use—but we are having lots of fun. Keep the photos and artwork coming.

EDITOR IN CHIEF
Stanley D. Klein, Ph.D.
Professor of Psychology,
New England College of Optometry

ASSISTANT EDITOR
Kim Schive

EDITORIAL STAFF
Andrew M. Bissaro
Valerie Steele

EDITORIAL INTERNS
Simone Albeck
Zlati Meyer
Annabel Tan

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING
Terri M. Sutera

VICE PRESIDENT, SALES
Kerry J. Cannon

AD TRAFFIC MANAGER
Stefanie Ferrante

CIRCULATION MANAGER
Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS
R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION
Lawrence Qualiano

FINANCE MANAGER
Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc.
Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 14.

BPA International Consumer Magazine Membership Applied for August 1993.

Shop 'til you drop. The phone.

1-800-600-7808, 1-800-755-0601(TTY). The Apple Computer Disability Solutions Store.

LETTERS

Steps Toward Adulthood

I was delighted to see the October cover of my son Jonathan with Kevin McHale of the Boston Celtics. I also want to share with you the next steps Jonathan has taken toward adulthood since his bar mitzvah.

After a year of volunteering at the North Shore Jewish Community Center, helping as an aide in a tot gym class and cleaning Nautilus equipment in the health center, Jonathan just landed his first paid job. He started work at Star Market. He's not nervous, but I am, as I have been with each new challenge he has ever taken. I don't know if he's ready, but I doubt my mother thought I was ready for my first job either. Star Market is another of a long line of community representatives who have given Jonathan the chance to be all that he can. He's been working for a month now. He pays taxes and contributes to the United Way.

I want to let your readers know that volunteer experiences are very important. On the application for the job at Star Market, there was a space to indicate volunteer work as well as paid employment. At only 14, Jon already had a pretty impressive resume.

As I reread Jon's bar mitzvah speech that was reprinted in October's issue, I remembered the first time he appeared in *Exceptional Parent*. He was two years old, and I had written an article called *Silence versus Signing*. In that article, I shared my struggles with the issues of Jonathan's lack of speech and the use of sign language. I don't know where the years have gone, but *Exceptional Parent* has been with us throughout, and I want to say thanks.

J.S., Massachusetts

"Inclusion"— Not Appropriate for All

I am writing out of great concern about the current trend of "inclusion" for all children with special needs. I am the mother of two sons with severe disabilities; they have a degenerative neurological condition called Batten disease. My sons have attended several different schools in the past five years, based on their educational needs. At age four, Ian and Joey began receiving services to address their developmental delays and need for intensive speech therapy. When the progress of the disease caused them to lose their sight, they attended the Maryland School for the Blind. We transferred them to their current school when they became totally physically dependent and unable to swallow, and developed a seizure disorder.

Clearly, our family has seen many sides of the special education system. Having a full range of available educational options allowed Ian and Joey to obtain the best education possible based on their ever-changing needs. This made a big difference in the quality of their lives.

The restriction of "options"—caused by the movement to "include" all children—will be detrimental for some children with special needs. The loss of small class size and close teacher-child relationships will result in less accurate assessment of a child's needs. Many children with severe disabilities have no more than nonverbal cues to communicate their readiness to learn a new task or just to interact. Without a close, intensive relationship, cues will be missed, and opportunities will be lost.

I am pleased that my children participate in some activities at the local ele-

EXCEPTIONAL PARENT

▸ *To reach out to parents of children with disabilities and special health care needs.*

▸ *To empower mothers and fathers by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

LARRY BELFORD, Director, Marketing Research & Strategic Analysis, Ciba-Geigy Pharmaceuticals, Summit, NJ
LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

256

mentary school and in the community. We have had no difficulty providing our sons with many opportunities for socialization. The care and education they receive from their teachers and the nursing staff in a small classroom could not be duplicated in a regular classroom.

"Inclusion" should be one of a variety of educational options for children with special needs. Current state and federal law requires school districts to provide a full continuum of special education placements—including separate schools. In fact, separate programming provides the most appropriate education for many children with special needs. The loss of options in the special education continuum of services will compromise our children's futures.

R.J., Maryland

EDITOR'S NOTE: This issue of Exceptional Parent *includes a thought-provoking guest editorial by Edwin Martin dealing with the topic of inclusion.* *See page 39.*

Article on Myoelectric Prostheses Misleading

I was saddened and dismayed to read your article, *New Technology for Artificial Arms* (November/December 1993). If an article so filled with misstatements, overstatements and demonstrably false statements appeared in a supermarket tabloid, it would come as no surprise. But, to have it appear in a magazine written for parents of children with disabilities is inexcusable. Parents look to *Exceptional Parent* for accurate, factual information, not fallacious hyperbole.

Saying that "...myoelectric prostheses come close to imitating the function of normal human arms and hands" is like saying that a 25-watt light bulb comes close to imitating the function of the sun. In the first paragraph your article says that Eden "grasps the wooden spoon firmly with both hands," but the photograph clearly shows that she has no grasp with her prosthesis!

Professionals in the field of pediatric prosthetics acknowledge that the overwhelming majority of upper-extremity child amputees will abandon their prosthesis by the time they are in their teens. No scientific study has ever been done, however, to determine if those who continue to wear a prosthesis into maturity enjoy any benefits—functional, social or financial—over those who do not. More importantly, no scientific study has ever compared the emotional health of the two groups. Prostheses are recommended based on an assumed need and assumed benefits, rather than on the basis of any body of scientific knowledge.

The most important factor contributing to a child amputee growing into a happy productive adult is a healthy positive self-image, but the factor most stressed in promoting the myoelectric prosthesis is its ability to conceal the missing limb. This emphasis on concealment teaches the child that a missing limb is a repulsive thing that must be hidden in order to fit into society. What a wonderful thing to teach a child!

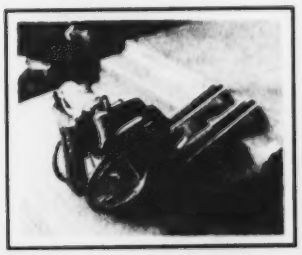
The sensory functions of the human hand are far more important than its manipulative ability. I believe that this is the reason most arm amputees find that their stumps or their feet are far more functional than the best prosthesis available.

In the 20 years that my wife and I have been involved in the amputee sup-

EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

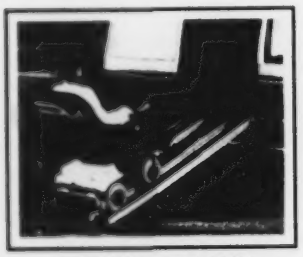
Look for this Seal of Quality



- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633
FAX 206-630-8196

Circle #40

port movement, it has been our privilege to know many amputees, not as patients but as friends. It is my impression that the happiest and most successful arm amputees are those who have discarded prosthetic devices and no longer feel a need to hide their limb deficit. Am I right? We'll never know until the child prosthetics industry starts dealing in scientific evidence instead of assumptions.

Until this happy day arrives, I would hope that *Exceptional Parent* will try to offer parents information that has some scientific foundation. This type of article would be more credible if an adult could be found to describe the benefits of a prosthesis rather than touting the accomplishments of a two-year-old.

B.B., Florida

EDITOR'S NOTE: We discussed this letter with resource persons at the Rehabilitation Institute of Michigan (RIM) who helped prepare New Technology for Artificial Arms. *The RIM clinic philosophy is that while a child with one arm and hand will be able to use substitution patterns and accommodations to accomplish almost every activity they encounter, these activities can be performed more efficiently with the use of a prosthesis. Clinic staff encourage the development of a child's positive self-image both with and without a prosthesis.*

Professionals at RIM agree about the need for research, but note that recent changes in prosthetic options, fitting techniques and training techniques make long-term studies difficult. Nonetheless, the Institute for Rehabilitation and Research (TIRR) in Houston, Texas, currently is in the process of surveying all upper-limb amputees in the United States to determine prosthetic wear and use patterns. Preliminary results show that only fifteen percent of children and seven percent of adults do not wear a prosthesis. Of those that do, 66 percent of children and 79 percent of adults report wearing their prostheses more than half their waking hours. This preliminary survey data contradicts the letter-writer's statement that "...the overwhelming majority of child amputees will abandon their prosthesis by the time they are in their teens."

A Hidden Disability

We receive *Exceptional Parent* in our office—I work for a neonatologist. I shared *Treatments for Attention Deficit Hyperactivity Disorder* (September 1993 book excerpt) with my daughter who has an eight-and-a-half-year-old son with Attention Deficit Disorder (ADD). It was very helpful. Please run more articles about this problem. We particularly need suggestions on helping other family members to be sensitive to a "hidden disability" like ADD. Relatives who are not faced with the challenge of an ADD child say things like, "That child just needs a good spanking and more discipline."

"The Cage," by Arsenia Levie, West Hartford, CT

Family members are not the only ones who need education about ADD; our school systems also are lacking in their abilities to cope. My grandson is a second grader this year. For the first time, he has a teacher who understands; the others do not. Thank you again for sharing articles on this problem.

J.C., Missouri

Fathers' Voices

As a professional in my state's Department of Mental Retardation and the father of a daughter who is experiencing developmental delays as a result of viral encephalitis, I was greatly encouraged to see James May's column.

When my daughter got sick two years ago, I underwent a radical shift in every notion and principle I had held regarding family relations, stress and the other emotions experienced by families of children with disabilities. Before that, I worked *for* families. Now, because of my firsthand experience, I have become someone who truly works *with* families.

One of the most glaring and alarming trends I have experienced is the lack of a role for fathers in families where a child has a disability. In general, society does not have a place for fathers outside the traditional boundaries of acceptable male behavior. I do not mean to paint with broad strokes here because fathers increasingly are changing their roles. But for the most part, men feel isolated and removed.

Mr. May's column encouraged me to act—I called him, asked for information and became a part of the National Father's Network. I have stepped up my efforts to develop a father's group in the region where I work.

Please continue to provide space in your magazine for *Fathers' Voices*. There are many fathers out here that want and need to hear about the ways in which they can take on positive roles for their children.

C.L., Connecticut

Keep Up the Good Work!

A brief note to compliment you and your staff on your marvelous magazine. Over the past several years, the quality has continued to improve, and the variety of topics covered makes each issue very informative and enjoyable.

My only criticism is that so very much of your magazine is dedicated to advertisements for equipment for persons with physical limitations. As the parent of a child with Down syndrome who—thank God—does not have physical limitations, I would love to see more articles and information directed towards other areas—recreational, vocational, medical and educational, to name a few. I look forward to your new departments and encourage you to keep up the good work!

S.R., Washington

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford

MOBILITY MOTORING PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just-plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford and Lincoln-Mercury Divisions

Circle #30

SEARCH

Encephalocele and Meckel Syndrome

I'm looking for information on encephalocele and Meckel syndrome. My daughter was born with an occipital encephalocele. I would like to find out the outcome of children born with this defect.

T.L.B., Tennessee

Daycare Dilemma

I am the parent of a seven-year-old girl who is hydrocephalic and developmentally delayed. After her birth we faced what so many other parents face—extreme difficulty in finding child care. I went back to school to pursue a career in nursing with the long-term goal of developing a local daycare center for children with special needs. Luckily, our daughter does not have any special medical needs, and we were able to find a local daycare program that was willing to accept her.

Now, due to our daughter's increasing size and complete dependence on others for everyday needs, we are having difficulty with our current daycare setting. Because of this, I have become highly aware of the problems faced by parents of children with special needs. With this in mind, I have decided to seriously look into what I need to do to fulfill my original goal of developing daycare for children with special needs.

At this point, I'm not sure what to do next and would like information on what is already available. If you have a child attending a specialized daycare center, I would like information on services provided and your likes and dislikes. If possible, I would like to get addresses of other places in the country that I may contact for guidance.

P.R., Louisiana

Good Books for Parents

I am a librarian working on building our library's collection of books and videos for parents of exceptional children. My primary concern is finding books that deal with the everyday challenges of parenting a child with physical or developmental disabilities or a child with a chronic illness. I also am interested in finding books written for parents of children who experience repeated or extended hospitalization to manage their medical conditions.

I will continue to note the titles mentioned in *Exceptional Parent* magazine but would also appreciate suggestions on other current, in-print materials suitable for parents—not medical professionals.

J.K., Oregon

Two Children with Down Syndrome

I am a teacher, and I work with a family who has two children. Both children have Down syndrome. They have a little girl who is two years old and a newborn son. This family is interested in hearing from another family who has two biological children with Down syndrome.

P.M., Minnesota

Benign Congenital Hypotonia

My two-year-old son, Matthew, has been "diagnosed" with benign congenital hypotonia. For a long time, doctors suspected hypotonic cerebral palsy. Gradually, his muscle tone has improved, and he is now walking. He has fine and gross motor delays and feeding problems. He is unable to eat table foods and is very small for his age. He also is delayed in his speech. Matthew receives weekly occupational and physical therapy.

During the last two years, I have felt very alone. Outwardly, my son looks like a perfectly normal one-year-old. It is hard for friends and family to understand. I would like to hear from other parents of a child with similar problems. I am also interested in hearing about any long-term problems associated with hypotonia. I understand it is associated with learning disabilities.

S.C., Virginia

Nail-Patella Syndrome

My son, Ian, has nail-patella syndrome, an easily diagnosed, but rare genetic condition characterized by nail dysplasia, bone deformities and sometimes, kidney failure. Ian is the first we know of in our families to have this. He has a full-blown case of nail-patella which is unusual. My doctors and I have been unsuccessful in finding another person or family that has or is a carrier of this syndrome.

The information we have on nail-patella syndrome seems to be quite dated. We are looking for up-to-date information on this condition. We would also like to find another individual or family with this syndrome.

C.M.T., New York

Norrie Disease and Cataplexy

We are the parents of two boys—Bobby, who is three years old, and Matthew, who is nine months old. They have a very rare, genetic condition called Norrie disease that always results in total blindness. In addition to the visual problems, both boys have physical and mental disabilities. They also have a 25 percent chance of losing their hearing.

After our nine-month-old was born, he appeared to be having seizures like our older son. After having tests run, we now know why the seizure medication did not work. They do not have seizures at all; they have a sleep disorder called cataplexy. We are looking for other parents who have a child with either Norrie disease or cataplexy. Please write.

B.F. & S.F., Washington

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard Street, Suite 305
Brookline, MA 02146-5005
Fax: (617) 730-0742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 St 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994)

260

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,

Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,

Role Models,

Point of View,

and

Corporations Who Care.

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34D1

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34D1

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

See reverse side for subscription details

Epidermal Nevus Syndrome and Lipomas

My two-year-old son has been diagnosed with epidermal nevus syndrome. The best description I can give is that raised, wart-like skin lesions cover the right side of his body. Application of a compound made with glycolic acid helps prevent thickening of the lesions which can cause infection when they become open. Complicating this skin condition are lipomas—fatty tumors—which continue to reappear despite two surgeries for removal of the larger ones on both sides of his body. On his trunk and arm, the skin lesions are in a line-type of design; on his leg, they just about cover the entire limb up through his buttocks. The right side of his body is much larger and longer than the left, the leg being the most prominent. In fact, his right leg is about three times the size of his left.

I am desperately seeking other parents or physicians who have knowledge of this disorder and can offer guidance as we go through future surgical procedures dealing with removal of the lipomas and/or skin lesions.

L.D., New York

Spastic Paraparesis

Our two-year-old son, Bryan, was diagnosed with spastic paraparesis when we first noticed unusual leg movements at about six months of age. Bryan's father also has this condition, so doctors believe that it is due to autosomal dominant inheritance.

Bryan, like his dad, is intelligent and managing his disability well. While developmental motor skills involving Bryan's legs are delayed, he uses his arms and hands well and is at age level in other developmental areas. He is a determined, active, happy two-year-old who is eager to learn and explore. When asked to do tasks requiring gross-motor movement, Bryan can clearly express his dislike of these tasks.

We would like to talk with families who share experiences similar to ours and who are considering various treatment options. We are also interested in sources of information or other resources we might use to learn more about spastic paraparesis.

R.T., Pennsylvania

Bleeding During Seizures

My two-and-a-half-year-old daughter, Brianna, has Aicardi syndrome, right parietal schizencephaly and infantile spasms that are uncontrolled. But here is the problem: When she seizures, blood comes from her mouth and sometimes her nose. This has been occurring for about one year, but has worsened in the last six months. Has anyone ever heard of this? The bleeding does not occur at any other time. She has been seen and tested by her neurologist, gastroenterologist, otolaryngologist and hematologist. None of these doctors could find a reason for the bleeding.

I would appreciate hearing from anyone who may have heard of this or who has another idea. I would also like to correspond with parents of a child with Brianna's diagnoses.

J.W., Pennsylvania

Ischemic Strokes

After a normal pregnancy and birth, our daughter, Tricia, was born seemingly healthy. Although she was somewhat behind in meeting developmental milestones, her pediatrician was not alarmed until her 12-month checkup. Then, she was referred to a specialist who diagnosed developmental delay and prescribed physical therapy.

At 14 months, Tricia suffered an ischemic stroke on the right side of the brain. It was caused by the occlusion of the right middle internal carotid artery. Extensive testing—including MRIs and an arteriogram—revealed no cause for the occlusion. Doctors decided that the artery had been malformed from birth and said that no more strokes were likely to occur.

At 16 months, Tricia suffered a second stroke on the left side of the brain. A week later, she suffered two more strokes, again on the left side. Now 17 months old, Tricia is essentially paralyzed and is fed through a nasogastric tube. Further tests, including a muscle biopsy, revealed nothing unusual other than some abnormal levels of amino acids and enzymes. Her doctors now think that she may have Moyamoya disease, although her characteristics do not really fit this diagnosis. The doctors can not tell us if Tricia will have more strokes.

We would like to hear from anyone else with a child who has suffered multiple ischemic strokes. We would also like to hear from any experts who have information that might help us. We believe that time may be running out for our little girl.

B.S. & T.S., Virginia

Haverich
ORTHOPÆDIC CYCLES
Europe's leading line of specialized bicycles, tricycles and tandems now available in North America.
Steel frame. Duel caliper, drum and coaster brakes available.
Parking brakes standard.
Latest styling and wide choice of colour combinations.
More than 30 specially designed accessories to meet every need.
Circle #36

RESPOND

Single Parent With Disabilities

P.D. (September 1993) is a single parent of a child with autism and other developmental delays. She also has disabilities of her own. She wrote of her feelings of isolation and her hope of finding "friendship and/or support."

When I saw your letter, I realized we are "neighbors." I am from Ohio too. I felt that I had to write and offer to be—well, whatever you want—a listener or a friend. The more we moms stick together, the more powerful we'll be, and the stronger we'll feel.

When I talk about my son to my friends with "regular" kids, I see their eyes glaze over. They just can't understand even though they want to. I think having a child with disabilities just magnifies all our normal emotions about parenthood. Our sorrow at our child's unrealized potential hits harder and sooner; our guilt at our inadequacies is much stronger and more often nags at us. And if our joy at the accomplishments of our child is sweeter because these accomplishments are so hard-earned, the joy is always tempered by the sorrow of knowing what a "regular" kid of that age would be accomplishing.

My David is almost six. He has cognitive and developmental delays and almost no speech. He's still in preschool, but we are approaching the time when he'll hit the school system. He has one younger sister who does not have disabilities. Wouldn't you know it—she is one of those compliant children, and it's so hard not to put too much pressure on her to "be good." I know it's not fair, but I can only handle one kid acting up at a time.

Call or write anytime. I don't work outside the home and know that it can be isolating. I'm interested in hearing how it's going for you.

L.S., Ohio

Undiagnosed

W.J.R. & T.R. (November/December 1993) were looking for a child who is similar to their 11-month-old son, Dakota. Dakota is developmentally delayed and has dysmorphic features which include slightly protruding, wide-spaced eyes; low-set ears; nose with flattened bridge; high palate and simian-creased left palm. His heart has an atrial ventricular valve dysplasia with a possible mild AV-valve stenosis. Extensive medical and genetic testing has failed to yield a diagnosis.

Our 13-month-old daughter, Meghan, was diagnosed at birth with a rare syndrome called cri du chat. Many of your son's features seem to resemble those of cri du chat. Like Dakota, Meghan has a flattened nasal bridge, low-set ears, low muscle tone, slow growth and smaller head size. She has a high pitched cry and, like Dakota, is developmentally delayed. Many children with cri du chat syndrome have simian-creased palms. Meghan also has a small hole in her heart.

Cri du chat syndrome is caused by the loss of genetic material from the short arm of the fifth chromosome. When the geneticist showed us Meghan's chromosome study, we could not even see the tip that had broken off, because it was so small. This could be easy to miss if the doctor does not know what to look for.

P.R. & J.R., New Jersey

☐ Your letter caught my attention because my nearly four-year-old daughter, Elena, also falls into that void of undiagnosed children. As I was reading your description of Dakota, I couldn't help but compare his development to Elena's at a similar age and think, "Gee, he's doing great!" At 11 months, Elena's developmental level was measured in weeks instead of months. She was nearly completely cortically blind, not at all alert and not a bit social. She went through a battery of tests comparable to Dakota's, and our family situation was exactly as you describe your own.

I spent more than a year dragging Elena from one neurology clinic to another, and from one EEG appointment to another. I read everything I could get my hands on that dealt with pediatric development, cerebral palsy, autism, mental retardation and anything else you could imagine, looking for a slot into which she might fit. But she didn't fit. Her "diagnosis" remains "developmental delay of unknown etiology."

I felt compelled to urge you not to drive yourself nuts looking for this elusive diagnosis or label for Dakota. In the end—with or without a diagnosis—he's just a kid. He's your kid. By now, he's just over a year old. He eats well. He's alert, happy and social; and he needs all the love and affection you can give him. He doesn't need to be dragged around for test after test, or to have conversation made about his facial features. As long as the tests to date have indicated no operable physical condition, what is the benefit of continued testing? Wouldn't you all benefit more if you spent that time, energy and money on things that can actually enhance your lives?

I don't mean to sound harsh, for I did the same thing as you. And I discovered that Elena's just a kid. She's in a fabulous program at the United Cerebral Palsy Developmental Center. She's starting to walk with a walker. She's seeing better and starting to get around a room pretty well to get the toys she wants. She's finger feeding herself, and she's a very content, pleasant kid—a kid with no diagnosis, and no label, and it doesn't make a bit of difference.

I hope you can hear what I'm trying to communicate. I'm not sure whether I would have been able to at that stage or not. But if not now, then maybe soon. I would be glad to offer any help I can.

Z.G., North Carolina

College With a Personal Attendant

N.T. (February 1993) is the mother of a 15-year-old daughter who is an honor student and wants to attend college. Her daughter has cerebral palsy and uses a motorized wheelchair. She needs extensive assistance for personal care. She has a great deal of difficulty writing, but as a one-finger typist, finds typing equally frustrating. N.T. wanted to hear about the college experiences of people with needs similar to those of her daughter. She also wanted information about colleges with good support services for students with disabilities.

I've worked with people with cerebral palsy for many years. I am also the

mother of a three-year-old boy with a disability. I want to start by congratulating you on the wonderful job you've done as parents. Your daughter's motivation to go to college is an excellent predictor that she will go on to have a productive life. Too many kids grow up believing that all kinds of things aren't possible because of their disability.

There is incredible technology available that has the potential to help your daughter in college. There are computer systems that are voice-activated rather than keyboard-driven. Your daughter might be able to use alternative devices to operate computers such as a joystick or a scanner with some sort of switch. You can get alternative keyboards, adapt standard keyboards to change key locations or change the length of time a key may be pressed.

You might start by calling the United Cerebral Palsy Association at 1-800-872-5827. Ask to speak to a referral person or to their resource person on rehabilitation technology. Your daughter should have an assistive technology assessment to determine the technology that would best fit her needs. Many large rehabilitation hospitals perform such assessments.

You should also call your state's Office of Vocational Rehabilitation (VR). They should get involved with your daughter before she leaves high school. I have known my state's VR office to fund the purchase of computers and other assistive technology, pay college tuition and pay for a personal care attendant for some college students.

Yes, your daughter *can* go to college. I know many people who don't write who have done so. I know one man with cerebral palsy who graduated with a business degree, works for one of the largest corporations in Pittsburgh and has started a printing business on the side. He does not write or speak. He has the use of only one finger.

Edinboro University, near Erie, Pennsylvania, has been accessible for years. They have many students with disabilities and excellent support services. Perhaps it would be worth a visit. Seeing people with all kinds of disabilities in a college setting undoubtedly would bolster your daughter's confidence.

S.G., Pennsylvania

EDITOR'S NOTE—Your state's Alliance for Technology Access (ATA) Center is another good source for information on assistive technology. In New York, contact Techspress, Resource Center for Independent Living, 409 Columbia Street, Utica, NY 13502, (315) 797-4642, (V/TTY). A complete listing of ATA centers appears in the Exceptional Parent 1994 Resource Guide *(January 1994).*

☐ I am a clinical social worker at Children's Hospital of Pittsburgh, and I read *Exceptional Parent* religiously. I am also a proud 1982 graduate of Ball State University in Muncie, Indiana. Ball State has earned national recognition for meeting the needs of students with disabilities. I was a personal care attendant for a fellow student during my freshman year. You can learn more about my alma mater by writing or calling Richard Harris, Director of Disabled Student Development, Student Center 307, Ball State University, Muncie, IN 47306, (317) 285-5293.

E.Y.N., Pennsylvania

SOMEWHERE OVER THE RAINBOW

WAY UP HIGH...

The dreams you carry, the wishes for something at the end of the rainbow,... hold on to them. In life, realizing your dreams takes more than a wish alone. It takes courage, hard work and determination,... even a little help from your friends.

permobil FOR KIDS

(800) 736-0925
6B Gill Street • Woburn • MA01801

© Permobil Inc. 1993

Circle #59

Helping Children Reach Their Goals

Our caring staff is committed to helping children reach their goals at every stage of their lives.

Specialized education and therapy programs are tailored to meet your child's needs.

Working together, we can help them reach their full potential.

. . . Right From The Start

Elwyn Inc. day and residential programs, include:

- early intervention
- pre-school for disabled and non-disabled children together
- elementary and secondary education
- post-graduation transitional services
- vocational training and placement
- award-winning therapeutic recreation facilities
- 24-hour health care services
- modern, home-like residential settings

Elwyn, caring for over 10,000 children and adults with varying disabilities, has locations throughout Pennsylvania, New Jersey, Delaware, California, and Jerusalem.

ELWYN INC. • Admissions Office
111 Elwyn Road • Elwyn, PA 19063-4699
(610) 891-2000 (PA) • (800) 345-8111 (outside PA)

Circle # 172

EXCEPTIONAL PARENT

120 State Street, Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)
Fax (201) 489-1240

Vice President Advertising Sales
KERRY J. CANNON

Sales Representatives

BARBARA H. ARNOLD (617) 259-9207 / Fax (617) 259-9883
New England, Upstate NY and East Canada

JONI JONES (516) 944-8068 / Fax (516) 944-2739
Greater New York

BARBARA NASTRO (201) 680-4874 / Fax (201) 680-8355
MidAtlantic (DE, DC, MD, NJ, PA, VA, WV)

WILLIAM MIDDLETON (404) 973-9190 / Fax (404) 565-7013
Southeast (AL, FL, GA, MS, NC, SC, TN)

ANTHONY ARNONE Phone & Fax (708) 428-5162
Midwest (IN, KY, KS, MN, ND, OH, SD, UT, CO)

JOHN MAISEL (708) 416-0780 / Fax (708) 416-0793
Midwest (IL, IA, NB, MO, MI)

KERRY J. CANNON (800) E-PARENT (372-7368) / Fax (201) 489-1240
Southwest (AR, LA, OK, TX)

RICHARD AYER (714) 366-9089 / Fax (714) 366-9289
West Coast (AZ, So CA, NV, NM)

WILLIAM HAGUE (206) 858-7575 / Fax (206) 858-7576
West Coast (AK, No CA, HI, ID, OR, MT, WA, WY, BC)

BARBARA NASTRO (201) 680-4874 / Fax (201) 680-8355
Schools, Camps, Residences, Classified & Special Sales

Ad Traffic Manager Stefanie Ferrante
EXCEPTIONAL PARENT
120 State Street, Hackensack, NJ 07601
(800) E-PARENT (372-7368) / Fax (201) 489-1240

BPA International Consumer Magazine Membership Applied for August 1993.

Subscriptions:

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

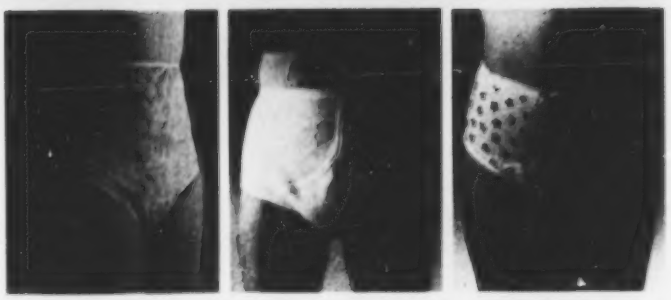
MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

The Next Step In Dealing With Incontinence

If incontinence is part of your life, you're not alone.

For millions, it's a fact of life. But now there's a better way to deal with it.

Now there's Hypersorb,™ a new technology that brings a new level of comfort and confidence to incontinence products.



For women and men, girls and boys: Hypersorb looks like activewear, works like incontinence wear.

What's more, it's also reusable, so it brings a new level of economics. And that's not all.

As you can see, it has the fashion of activewear, so it will appeal to everyone from children to seniors.

We know it works; it's been working for years throughout Europe under the brand name Ganmill.

Even uncompressed, it's only 4mm thick, so it can be used in a variety of fashionable designs.

You'll also notice that there's a lot less bulk than you expect in an undergament that works so well.

And it keeps working a long, long time. After multiple washings, its absorbency is still 1000%. Which means it can save you quite a bit of money over disposables.

Even better, this also works for our environment. We use only pure polyester and viscose fibers; add no chemical binders or wood pulp products.

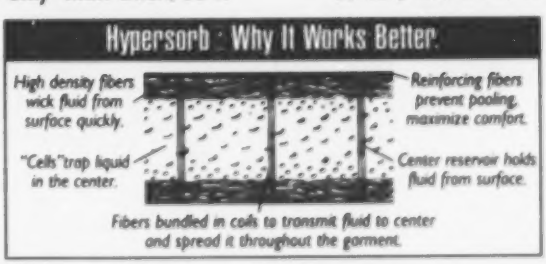
All told, we believe that Hypersorb will work better than whatever you're using now.

But talk is cheap. We back that up with a One-Year Guarantee. Follow instructions, and if Hypersorb doesn't keep working, send it back. We'll give you a new one or your money back.

So call, write or fax us. MasterCard, Visa and personal checks are accepted. Do it now.

Because you've got nothing to lose.

And you've got a much better way of dealing with incontinence to gain.


Hypersorb : Why It Works Better
High density fibers wick fluid from surface quickly.
"Cells" trap liquid in the center.
Reinforcing fibers prevent pooling, maximize comfort.
Center reservoir holds fluid from surface.
Fibers bundled in coils to transmit fluid to center and spread it throughout the garment.

Ganmill
Personal Healthcare & Hygiene

HYPERSORB PATENT PENDING

TMI
TECHNOMARKETING INC

307 Bacon Road • Rougemont NC 27572 • (919) 477-1387 • Fax (919) 477-2294

Circle #122

GM MOBILITY PROGRAM

Maintain your daily independence through the General Motors Mobility Program for the Physically Challenged.

It starts with a toll-free call to our GM Mobility Assistance Center. We'll identify your local driver assessment centers, list your area's installers of adaptive driving devices or vehicle modifications and suggest which GM cars and light-duty trucks might work best for you.

Next, whether you buy or lease a new GM vehicle or dealer demo model, we'll reimburse you for the cost of adapting it–or for the reinstallation of your own adaptive equipment–up to $1000.

(Reimbursement for leased vehicle adaptation available only upon lessor's approval to adapt vehicle.)

We're making every day Independence Day.

Qualified customers can finance the cost of the vehicle and any modifications through GMAC in a single transaction at participating dealers.

The people at GM, and GM dealers nationwide, know how important mobility is to your everyday life. Call us today. Or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer and find out how the General Motors Mobility Program can help make every day Independence Day for you.

- **Call toll-free: 1-800-323-9935 (TDD users: 1-800-TDD-9935)**
- **Information on driver assessment centers and adaptive equipment installers**
- **Reimbursement of adaptation costs, up to $1000**
- **Financing available through GMAC**

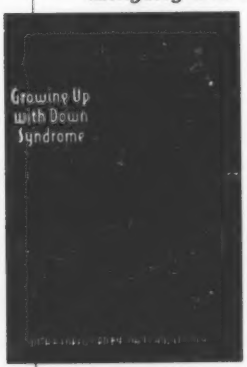
General Motors

Jason Kingsley and Mitchell Levitz

Young authors challenge stereotypes and misconceptions

***Jason Kingsley** is a high school senior and former associate board member of the National Down Syndrome Congress. He has acted in films and on television, and currently lives in Chappaqua, New York. **Mitchell Levitz** graduated from high school in 1991. He is active in politics, has worked for two state assembly members, and presently lives and works in Peekskill, New York.*

Kingsley and Levitz spoke to Exceptional Parent *while in Boston during a 10-city publicity tour to promote their recently-published book* Count Us In: Growing up with Down Syndrome *(Harcourt Brace, 1994), available through* Exceptional Parent Library, *(800) 535-1910.*



Mitchell: I think that all people can succeed if there are opportunities out there for them. It is very important for children to get the education that they need. Second, it is important to be in the community by having social activities and making friendships. Once people get to know us, then people will be very accepting of us.

Both me and Jason are in regular education and special education—we have a combination of both. I want to see more people with disabilities included in regular education. They are capable of going to a regular school with other students. They can learn the same as anyone else. Some people with disabilities take longer to learn than other individuals, but no one should be discriminated against. A very long time ago, there were many cases of discrimination, misconception and stereotyping—but that was in the past.

Jason: I took courses like math, science, and history. I was placed with people with mild disabilities, in what is called special education. But, like Mitchell said about inclusion, I do have other courses that are not special education—like gym and typing. Also, I am in the drama club.

Teasing

Mitchell: Sometimes, people will put you down or tease you because of your disability. Me and Jason try to encourage other students not to do that. First, they hurt our feelings. Second, it is not appropriate behavior because it is not right to make fun of someone with a disability or a different race. We are all individuals. We all have rights and no one should bother those rights.

When I was in school, I wanted to be part of the popular gang, to be in the crowd. There is peer pressure. People would take advantage of me because of my disability. They thought they could get away with it, and back then, they did get away with it. And now I'm here telling people, "Hey, this not right and you better stop it."

Jason: When I was in middle school, there was a lot of teasing. I didn't like the teasing. People teased me because they thought that teasing was cool. I was treated unfairly. The principal took me to suspension one time. I didn't think that I did something wrong.

Jason and Mitchell, at Mitchell's high school graduation in 1991.

Another kid did something wrong—he was trying to tease me—but I got suspended.

I got into high school—that was when I was a freshman—and there was less teasing than middle school. Now that I'm a senior, I truly believe that people are believing in me, trying to be very supportive.

A strategy that I used to deal with the teasing was that I talked to the dean or principal or my teacher. And I talked to my parents, my grandparents and my friend, Mitchell Levitz—that's why we say "friends forever!" I also go to a psychologist once a week. He's teaching me how to think on my own. I don't need him anymore because I can solve problems on my own from now on.

Meeting Big Bird: *As a pre-schooler, Jason Kingsley made several appearances on Sesame Street. His mother, Emily, is a writer for the show.*

Mitchell: Yes, I remember when Jason was having problems in school, and he would ask me for advice on how to handle a situation. I gave him lots of advice. I indicated to him that he had to talk to the right people, that he needed to speak up in order to handle his problems.

My situation was different because I went to school with my two sisters. They were very supportive and very understanding. They helped me solve my problems.

Hopes and Dreams

Mitchell: I would like to tell parents that they should give us a chance to be ourselves and to make decisions on our own. It is understandable that parents can be overprotective. Sometimes our parents feel protective of both me and Jason.

Jason: I also would like parents to learn to let go of their children, give us the same opportunities parents had as children.

Mitchell: We have some limits—like driving. Driving is a strong responsibility. You need to learn all of the technical skills to drive. It is very difficult because it takes us longer to learn. That is part of our disability. A person who drives needs to make quick judgments. That is something that is very difficult for me. My parents have told me that there are some judgments I make that are not that good.

5 Models Available Now

The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

Special Discount offered until 6-1-94

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Hedstrom Corp. of Bedford, PA

Circle #43

PROTECTION PANTS

Swimsuit Diapers

Prevents Ebarrassing Pool Accidents
Soft, lightweight, outer layer with wick-away inner lining. Tapered design provides protection under a regular swimsuit.

INFANTS ($9.95)
S, M,L, XL, SL
YOUTH ($14.95)
4/5, 6/7, 8/9, 10/11, 12/13,14/15
ADULT ($17.95)
S, M, L, XL

Dry Night Pants

Keeps Outer Clothing or Bedding Dry
Reusable, comfortable pants offer wetness protection. Waterproof knit outer layer with super absorbent inner pad. Holds one cup liquid.

YOUTH ($18.95)
2/3, 4/5, 6/7, 8/9, 10/11, 12/13, 14/15
ADULT ($21.95)
S, M, L, XL

Shipping $3.95
Visa/MC Accepted
Ask for free catalog

Family Clubhouse
6 Chiles Ave.
Asheville, NC 28803
1-800-876-1574

Circle #174

The other thing I want to mention is that I always dreamed of having a child of my own. I know that it is irregular for a person who has Down syndrome to father a child, but I want to have the same lifestyle as everyone else.

Some people thought we would not be able to write a book. We have proven them wrong. We are trying to erase all the negative attitudes that people had about Down syndrome.

Jason: Not everyone has the same hopes and dreams, but we are heading toward the same goal—independence.

I am a senior now. I have passed all my courses to get a regular diploma. I am going to graduate this June. We are thinking of a graduation party and all that stuff. And from there, we are looking at post-secondary colleges. Later, I am going to get a business and live on my own. I dream to be a father with kids, but we will get into that when the time comes.

Mitchell Levitz, playing soccer at age 10.

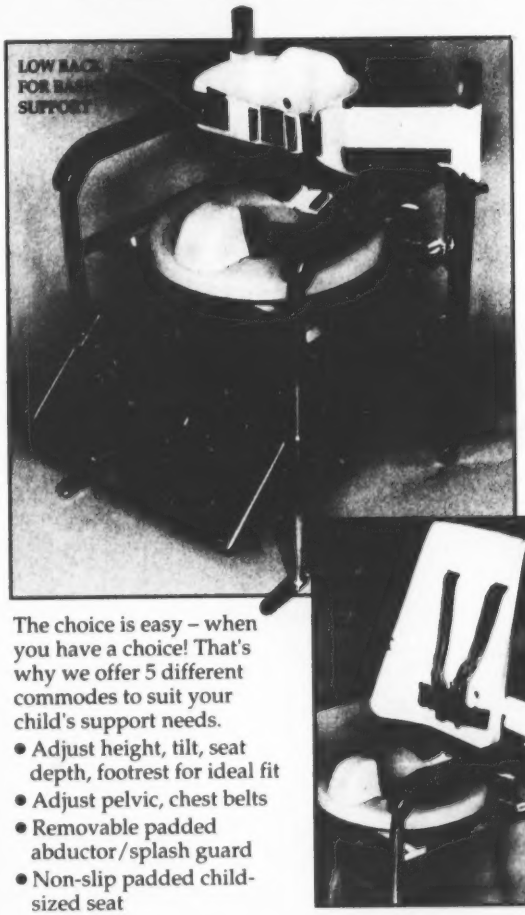
Mitchell: I graduated in 1991 with a regular diploma. I am currently working at the Chamber of Commerce in Peekskill, New York. Recently, I interviewed for a new position—coordinator of consumer empowerment for Westchester County ARC. I will be filling that position next month. I will be speaking to schools, going out to the job sites and helping to organize fund-raisers. In time, I might decide to run for public office.

I am independent now—living in a house by myself which is nearby my parents. I was in a program to get ready to live fully independent. They taught me many different kinds of skills—how to cook, shop, do my laundry, finances or whatever. Since September, I have been living by myself. I felt very mature and very strong to make this decision to live independently.

271

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet



The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle #11

Infa-Dent®

Finger Toothbrush and Gum Massager

* GENTLY CLEANS TEETH
* MASSAGES GUMS
* EASY TO USE

Available At Your Nearest Drug Store

Or Call 1(800) 868-8338

Nu-Tec Health Products,™ Inc

Circle #56

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle #86

Unlocking Doors

Mitchell: What is unique about our book is that it's in conversational form. And even though there are many other books written about Down syndrome, there has never been a book written by two young men who have Down syndrome. Some people thought we would not be able to write a book. We have proven them wrong. We are trying to erase all the negative attitudes that people had about Down syndrome.

Jason: This book is about misconceptions and stereotyping. We hope people with disabilities will be accepted in the community.

Jason and prom-date Tami Roskies.

Strangers can become our friends. We have seen some strangers during our book tour. They say, "Hey! I know these guys from seeing them on CNN." So are these people really strangers? People say, "Oh, I saw you on TV, and good luck with your book." People are becoming aware and becoming our friends.

Mitchell: I would like to add that it is a positive influence on society if they show people like us on television talking about Down syndrome. Let me give you one example—the television show *Life Goes On.* That show has shown that we have the same capabilities as everyone else. It really makes me feel good knowing that people understand how we feel.

My message is that people with disabilities want to be accepted. They want to have opportunities for life. I just want to erase all the negative attitudes in society.

Jason: My message is that people with disabilities have hopes, dreams, goals and feelings—the same as everyone else. I want to use an analogy: There used to be locked doors on the "museum of life." But with "the key of opportunities," people with disabilities can open up those doors for many possibilities. Each room has a new adventure. And now, people are coming into the museum. They should be coming in, because we don't want any limits on expectations for us. We have to have high expectations. One of the rooms in my museum is going to be about higher expectations for parents and for children.

272

NEW IMPROVED QUICKER-ACTING FORMULA
DISSOLVES INSTANTLY IN LIQUIDS

To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call... (800) 333-0003.

413

Circle 169

All in the Family

by Kate Divine McAnaney

It's family vacation time again. Time to make plans—Where shall we go? What shall we do? Who will join us?

A friend calls. We've been on vacation with her family before. She wants us to go camping with them. It sounds like fun. I consider the place she suggests and wonder aloud, "Are there any pathways that will be paved or smooth enough for our son's wheelchair to safely cruise along? Will the campground have an area flat enough for him to maneuver without assistance? Can he get to the marina so he can fish?"

For our family, these are the types of questions that we think about before we go anywhere. Such concerns seem normal to me. I'm not distressed or particularly frustrated by them, so I'm surprised when my friend perceives my questions differently. She heaves a deep sigh as if to say, "What a burden for you!" Then she proceeds with a suggestion that stuns me—"Have you ever thought about not taking Mahlon? Maybe leaving him somewhere…?"

I want to laugh. *Leave him? Where? On the roadside? At home alone?*

At the same time, I want to cry because it's so hard to get people to understand that Mahlon is family. I want to shout at her—as if that would make her understand more easily. "A family vacation without part of the family? Are you kidding? He's our child! He likes to be with us and do the things we do. He likes to camp and fish and ride in the boat. He likes to gather with everyone around the campfire to sing and listen to jokes."

Misjudging my silence as consensus, my friend plunges forward to explain that it would be good for us to do some things without our son to hold us back. It would relieve our burden, free us from the obligation to tend to his needs.

Whoa—now I'm insulted! As if my 16 years as the parent of a child with special needs hasn't taught me that I have to take care of myself. I do take time for myself! I write, read, go to the movies, indulge in long phone calls, have lunch with friends and spend time alone with my husband. My husband and I also focus some exclusive attention on each of our children, according to their interests and abilities.

Who does she think she is? I can appreciate my friend's concern, but not her insensitivity. Rather than answer her unintentional affront with one of my own, I make an excuse to end the conversation. I tell her I'll think about it.

Defining "Family"

In reality, I don't need to give my friend's suggestion a moment's consideration. I have a very definite sense of what "family" means to me. In my definition, it includes both of my children. But I need to think about how to explain that to her. I want her to understand what it is like to be the parent of a child with special needs. I want her to know that it's like being the parent of any child and that the child with special needs is an important part of the family unit.

I appreciate it when friends are concerned about me and my life as an exceptional parent. I feel supported when they acknowledge that I'm doing a great job with my son. I always listen to their suggestions and try to hear them without becoming too defensive. I know from experience that some very useful suggestions come my way. Once, after telling someone that I had to get up nearly every night to turn Mahlon over, the person said, "You know, I wonder if you could screw a towel bar onto the wall beside his bed so he could pull himself over?" I immediately recognized that suggestion as a jewel. I went home and did it, and it worked! I wish I could think up all the good ideas by myself, but I have to admit that I can't. Sometimes, the obvious is difficult to see, so I try to keep an open mind when someone makes a suggestion. I constantly sort the useful from the ridiculous,

274

the helpful from the insulting and the supportive from the insensitive.

My friend's suggestion that we exclude Mahlon because he has cerebral palsy and uses a wheelchair is easily categorized as ridiculous, insulting and insensitive. Would she also suggest excluding a child who has obnoxious habits? I have been on group outings where I had to endure other people's children who were far more troublesome than the relatively simple logistical problems posed by my son's wheelchair.

(ABOVE) Mahlon (left) and brother Michael at Lake of the Woods, Oregon. (RIGHT) ***Soaking up some rays:*** *Kate and Mahlon enjoy an afternoon on the beach at Lake of the Woods, Oregon.*

Every Family has Limitations

I try to put my hurt feelings aside. I tell myself that my friend's suggestion arose from her lack of experience rather than any malicious intent. I realize that she is looking at my life from the outside and imagining herself in my place. The tasks, the special preparations and the efforts that I have come to take for granted seem overwhelming to her. Or maybe she *can't* imagine herself in my position because it's unsettling and uncomfortable for her to look at my life.

I want to tell that I was uncomfortable at first, too. I didn't think I would be any good at this kind of parenting either, but I've learned along the way. When I chose to become a mother, I decided that I was willing to take any child I got. Since then, I have asked myself what I would have done if I had known before he was born that Mahlon would have special needs. I don't have an answer. I really don't know what decision I would have made, so I don't judge anyone else's decisions on that issue. It's too easy to moralize about someone else's life when you're not in their shoes.

I do know that when my son arrived prematurely and managed to survive despite his low birth weight and immature lungs, I was hooked. I didn't care what special needs this little fellow would have—I loved him. I was his mother!

As time passed and his needs became obvious, my feelings about him didn't change. He didn't "become a burden" or "create an obligation." He was still just my child. I never even considered not helping him in every way I could. I didn't even think about not including him in my life. He was family.

Certainly, there have been frustrating times, annoying situations to deal with and overwhelming tasks to accomplish. But we plod along, one step at a time, trying to find humor in our experiences. Yes, our life is limited in some ways, but so what! Every family lives within some limitations—economic, occupational, geographical or even self-imposed. The fact that our son uses a wheelchair is just a fact of life.

Our family can't enter every building through the front door, but we've sometimes found it far more interesting to enter through the back. When we toured the White House, my son was able to enter through the kitchen and ride in the President's eleva-

FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE

Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- Aquatic Aids/Sports Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE INC.

150 No. MacQuesten Pkwy., Suite 95307 Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

Circle #29

Laureate

TALKING SOFTWARE FOR SPECIAL NEEDS

Free Book!

Laureate's book, *Sequential Software for Language Intervention*, describes seven stages of language development from birth to adulthood. Learn how our talking software can improve your child's communication skills.

Call for a FREE BOOK and our new 1994 catalog.
1-800-562-6801

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Circle #48

tor to join the tour group on the second floor. He watched the kitchen staff prepare the President's lunch and discovered that the President himself had used the same elevator just ten minutes before—quite a thrill for a boy who loves American history!

On that same trip, we got to enter the National Archives building through a service entrance. We walked past cases of documents that were no longer on public display and some that were waiting to be cataloged. It was fascinating for all of us. Sometimes just finding an accessible door or an elevator is an adventure in itself. Other times it's annoying. We have done it for so long, that we don't think about it much anymore.

Family vacation: *(from left) Kate, Mahlon, Michael and Patrick at Multnomah Falls, Oregon.*

Willing to Make Things Work

How can I explain to my friend that I love my son just as much as she loves hers? How can I make her see that what she perceives as a burden, I see as a loving commitment? How can I convey that *she* is the one who doesn't know how to live with disabilities, not I?

It's family vacation time, but I don't think we will go camping this year. I think we'll try something more dramatic—like traveling by train through Europe. Maybe, by seeing that, my friend will realize that we are willing to make things work. We are a family who enjoys traveling and sharing experiences. *Where* we go, *when* we go, and *how* we go will always be affected by the fact that one family member is in a wheelchair, but one thing is certain—as long as our children want to travel with us, we will go on family vacations with the *entire* family.

Kate Divine McAnaney is a counselor and advocate for United Cerebral Palsy of Monterey and Santa Cruz Counties, California. She has written several articles for Exceptional Parent, *and is the author of* I Wish... Dreams and Realities of Parenting a Child with Special Needs *(UCPA 1992; ISBN 0-9632338-0-7; $8.95, available through* Exceptional Parent Library). *She lives in Carmel Valley with her husband and their two sons.*

276

SUMMER FUN

An Exceptional ey

By David and
Susan Brooks

Peter plays at the "Honey, I Shrunk the Kids" play area at Disney–MGM Studios, Disney World.

Before our son was diagnosed with autism, we had a timetable for life's important vacation rites. We had planned trips to the circus, visits to the zoo, tours of museums and, of course, that pilgrimage to America's middle-class Mecca—Disney World. As far as the Disney trip was concerned, we had agreed to wait until our two children, five-year-old Stephanie and four-year-old Peter, were old enough to appreciate and remember all the rides.

Peter's diagnosis resulted in many changes for our family, but our vacation plans remained the same. Our family vacations have become experiments in disability-access planning and tests of our son's emerging abilities. As we mastered short visits to relatives and day trips to petting zoos, we knew the true challenge was still ahead—we wanted to make a trip to Disney World and live to tell about it.

This article is the story of our trip. We hope other exceptional families will be able to benefit from our experiences. It wasn't a perfect vacation, but it was very rewarding for all of us.

Logistics and Planning

A lot was involved in taking a four-year-old child with autism on a tour of Orlando's major tourist attractions. Our first step was to make an honest assessment of our son's abilities and needs. Despite his autism, Peter is generally a well-behaved child. He has some speech and is toilet-trained. Unlike some children with autism, he is not distressed by changes in his routine or environment. However, he does engage in some self-stimulatory behavior that is quite noticeable, and appears quite odd to most passersby. He also has occasional tantrums.

Since autism is not a physically "obvious" disability, my wife and I were concerned about other people's reactions to Peter's occasional odd behaviors and apparent inability to understand speech. More worrisome was Peter's absolute lack of patience. Throwing him into the "endless" lines of one of the world's most popular resorts was a frightening prospect.

In speaking to another family of a child with autism, we learned that the Disney organization is very accommodating toward people with all sorts of disabilities. We called Disney, and after several transfers to the wrong department, finally reached Disabled Customer Services.

Our first question had to do with Disney's policy toward "non-obvious" disabilities such as autism. As we had hoped, the Disney representative was helpful and understanding. She explained that a "special assistance pass" was available. This pass could be used to obtain preferential access to many attractions. The customer service representative asked only that we use the pass with discretion—we should wait if the lines weren't long and our child was handling the situation calmly. Our special assistance pass and related brochures on accessibility to the Disney resorts arrived in the mail within a week.

Off to Disney!

One of the benefits of frequent flying is the nonchalant attitude you get when boarding an airplane. Though not a frequent flyer, Peter took the trip in stride. In fact, his enthusiasm and engagement surprised us. He peered out the window intently during the flight, quietly watching the world from above the clouds.

The only problem we encountered that day occurred with a long wait for a rental car at the Orlando airport. After 10 minutes in line, Peter began to scream and writhe on the floor—behavior that might go unnoticed in a two-year-old, but we got more than a few stares. We managed to treat the tantrum as "just-your-normal-everyday-kid-throwing-a-fit" and finally got our car. We arrived at the hotel, jumped in the pool and tried to plan our next day's activities.

Revenge of the Flying Dumbos

We decided to tackle the Magic Kingdom first. We approached the parking lot and paid our four dollars. We could see the top of Cinderella's Castle over the tops of the distant trees. Squeals came from the back seat as we pulled into an empty parking space. Since it was mid-November, the parking lot was not crowded, and we were able to park quite close to the entrance. We applauded our good fortune, boarded the Magic Tram and set off on our adventure.

Stephanie found the monorail thrilling, and her excitement was contagious. By the time we had arrived at the Magic Kingdom rail station, Peter began to bounce, hopping up and down in anticipation of what lay ahead. We began by boarding an old-fashioned car for a ride down Main Street USA to Cinderella's Castle.

"Rella, Rella!," Peter shouted as we got out of the car and admired the scene from a favorite fairy tale. His eyes lit up with joy as he walked up the staircase.

My wife and I exchanged knowing glances of self-approval, as if to say silently, "Yes, we really did make the right decision to bring Pete." Of course, that was *before* we saw the Flying Dumbo ride.

Peter spotted it first. "Dumbo! Dumbo!," he cried as he pulled eagerly against my grip. Peter had always enjoyed the movie *Dumbo*, and seeing his favorite story come to life was almost too much to bear.

"Dumbo! Dumbo!," he yelled. Stephanie wanted no part of this "kiddie" ride and towed Susan to the merry-go-round. Peter and I got in line for the Flying Dumbos.

Peter and sister Stephanie meet a favorite Disney character.

Accessible Orlando

- The Orlando/Orange County Convention and Visitors Bureau can offer recommendations and tips for accessible travel, as well as general information about area attractions. They can be reached at (407) 363-5871.
- Walt Disney World has an excellent *Guidebook For Guests With Disabilities*. To get a copy, call (407) 824-4321, voice or (407) 827-5141, TDD. For information on accessible Disney accommodations, call (407) 934-7639, voice or (407) 345-5984, TDD.
- Universal Studios Florida has prepared a thorough *Studio Guide For Guests With Disabilities*. For a copy, call (407) 363-8000, voice or (407) 363-8265, TDD.
- Sea World features wheelchair seating at all facilities, as well as wheelchair rentals. For further accessibility information, call (407) 351-3600, voice or (407) 363-2617, TDD.

The only problem was that Susan had taken the special assistance pass and left me stranded with a very excited and impatient four-year-old who could not understand why he had to wait.

His screaming, kicking, yelling and crying went beyond normal tantrums. When that didn't persuade me to put him on the ride immediately, he began the repetitive sing-song sounds he makes to calm himself. I finally noticed the stares as other parents watched this odd display. "Watch the kicking," a woman said, not to me but to her daughter.

Another 30 minutes of kicking and whining passed before we boarded Dumbo for our 90-second joy ride. "Timmy Mouse! Timmy Mouse!," Peter shrieked as he spotted Dumbo's diminutive friend perched above the mirrored ball in the center of the ride. Round and round we spun, up and down, flying as Dumbo does in the movie. The ride was much too short.

New Survival Tactics

After the "Dumbo Incident," Susan and I agreed to stick together and use the special assistance pass whenever necessary. We also decided to make advance plans by scouting out each ride first—Where is the special entrance? Can we go "in" the "out" door? Are the lines too long? Is the ride worth the effort?

With our new survival tactics, we spent the rest of the day wandering happily through the Kingdom, enjoying the park like any other "unexceptional" family.

Peter's favorite rides were very fast and very physical. He had little interest in movies or live shows like the *Country Bear Jamboree*, but he loved *Thunder*

278

Mountain Railroad, Flight to Mars and *Peter Fan's Flight*. He had less interest in slow moving rides like *It's a Small World* or *Pirates of the Caribbean*.

With the help of the special assistance pass, our trip was very enjoyable. Perhaps the most difficult challenge was getting Peter to "transition" from one good experience to another.

Should You Go?

Despite the challenges, we plan to return to Disney World again in a few years with Peter and Stephanie. Access for children with developmental disabilities was good-to-excellent, and we feel that the experience was a good one for Peter.

Despite the lack of obvious physical disabilities, Peter was never denied access to the special entrance of any ride. Most of our Disney hosts were accommodating and unquestioning of the legitimacy of our pass, although a few had never seen one and studied it carefully. Everyone treated us with respect and courtesy.

Susan Brooks with Peter.

We also had good experiences at EPCOT and Disney/MGM Studios, except that both kids found EPCOT to be much too "slow"—with the exception of Met Life's *Body Wars*, Norway's *Maelstrom* log flume ride and GE's fireworks and light show.

Traveling during the off season is the only way to go. The normal spring and summer crowds are difficult for most families to handle, and would be impossible for most families with special needs. Though the park is only open until 7 p.m. during fall and winter seasons, you can still pack a lot into a day by getting an early start.

Before you make the trip, weigh the pros and cons in terms of your family's special needs. The normal hassles of any family vacation are magnified by the special problems associated with your child's disability.

The hassles are often worth it, however. The stress fades as you look back on the fun moments. Your children who don't have disabilities will have a vacation experience like those of most of their friends. Your child with a disability will receive respectful accommodation of his or her special needs. And parents will create singularly unique family memories.

David and Susan Brooks live in Morris Plains, New Jersey, with their two children, Stephanie and Peter. David is a marketing communications manager. Susan, a former business systems analyst, is an active member of the parents association at Peter's school, The Developmental Learning Center in Chatham, New Jersey.

279

kid-kart™
cares about kids.

kid-EZ tilt/recline™

made in USA
PATENT PENDING

Proving good looks, convenience and proper positioning work wonderfully together.

kid-EZ Adjustable High Chair Base

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle #46

Travel Resources

The following government offices can offer referrals and information about accessible services, accommodations, attractions and tourist destinations in each state (USA) or province (Canada).

ALABAMA
Dept of Tourism
401 Adams Ave, Ste 126
PO Box 4309
Montgomery, AL 36103-4309
(800) 252-2262
(800) 548-2547, TDD
(205) 242-4169
(205) 242-4717

ALASKA
Alaska Division of Tourism
PO Box 110801
Juneau, AK 99811-0801
(907) 465-2010

ARIZONA
Office of Tourism
1100 W Washington
Phoenix, AZ 85007
(800) 842-8257
(602) 542-8687

ARKANSAS
Dept of Parks and Tourism
One Capital Mall
Little Rock, AR 72201
(800) 644-4833
(501) 682-7777, V/TDD

CALIFORNIA
Office of Tourism
801 K St, Ste 1600
Sacramento, CA 95814
(800) 862-2543
(916) 322-1397

COLORADO
Denver Commission for People with Disabilities
303 W Colfax, Ste 150
Denver, CO 80204
(303) 640-3056
(303) 640-3840, TDD

CONNECTICUT
Development and Tourism
865 Brook St
Rocky Hill, CT 06067
(800) 282-6863
(203) 258-4355

DELAWARE
Tourism Office
99 Kings Hwy
PO Box 1401
Dover, DE 19903
(800) 441-8846

DISTRICT OF COLUMBIA
Convention and Visitor Ctr
1212 New York Ave NW
Washington, DC 20005
(202) 357-1697
(202) 962-1825
(202) 472-5265

FLORIDA
Division of Tourism
126 W Van Buren
Tallahassee, FL 32399-2000
(904) 487-1462

GEORGIA
Dept of Industry, Trade and Tourism
PO Box 1776
Atlanta, GA 30301
(800) 847-4842
(404) 656-3590

HAWAII
Hawaii Visitor's Bureau
2270 Kalakaua Ave
Honolulu, Hawaii 96815
(800) 257-2999 (recording)
(808) 923-1811
(808) 546-2565, TDD

IDAHO
Dept of Commerce
PO Box 83720
Boise, ID 83720-0093
(800) 635-7820
(208) 334-2470

ILLINOIS
Central Illinois Tourism Council
629 E Washington
Springfield, IL 62701
(800) 822-0292
(312) 793-2094

INDIANA
Dept of Commerce Tourism Division
One N Capital, Ste 700
Indianapolis, IN 46204
(800) 382-6771
(317) 232-8860
(317) 2[illegible]-5977, TDD

IOWA
Dept of Economic Development Tourism Division
200 E Grand Ave
Des Moines, IA 50309
(800) 345-4692
(515) 242-4705

KANSAS
Dept of Commerce and Housing
Travel and Tourism Development
400 SW Hanison, Ste 1300
Topeka, KS 66603-3712
(800) 252-6727
(913) 296-2009
(913) 296-3487, TDD

KENTUCKY
Dept of Travel Development
Capitol Plaza Tower
500 Mero St, Ste 2200
Frankfort, KY 40601
(800) 225-8747
(800) 225-7275, TDD
(502) 564-4930

LOUISIANA
Louisiana Tourism Center
PO Box 94291
Baton Rouge, LA 70804-9291
(800) 334-8626, V/TDD

MAINE
Publicity Bureau
PO Box 2300
Hallowell, ME 04347
(800) 533-9595
(207) 623-0363

MARYLAND
Dept of Tourism
217 E Red Wood St, 9th Fl
Baltimore, MD 21202
(800) 445-4558, Ext 103
(800) 735-2258, TDD

MASSACHUSETTS
Office of Travel and Tourism
100 Cambridge St, 13th Fl
Boston, MA 02202
(800) 447-6277
(617) 727-3201

MICHIGAN
Michigan Travel Bureau
333 S Capitol
Lansing, MI 48909
(800) 543-2937
(800) 722-8191, TDD

MINNESOTA
Office of Tourism
121 E 7th Pl
Metro Sq
St Paul, MN 55101
(800) 657-3700
(612) 296-5729

MISSISSIPPI
Metro Jackson Convention and Visitor's Bureau
PO Box 1450
Jackson, MS 39215-14500
(800) 354-7695
(601) 960-1891

MISSOURI
Division of Tourism
PO Box 1055
Jefferson City, MO 65102
(800) 877-1234
(314) 751-4133

MONTANA
Travel Montana
PO Box 200533
1424 9th Ave
Helena, MT 59620
(800) 847-4868
(406) 444-2978, TDD

NEBRASKA
Nebraska Tourism
PO Box 30370
Lincoln, NE 68509
(402) 471-5497

NEVADA
Commission of Tourism
Capitol Complex
Carson City, NV 89701
(800) 638-2328
(800) 326-6868, TDD

NEW HAMPSHIRE
New Hampshire Tourism
PO Box 1856
Concord, NH 03302
(603) 271-2665

NEW JERSEY
Office of Travel and Tourism
CN-826
Trenton, NJ 08625
(800) 537-7397
(609) 292-2470

NEW MEXICO
Dept of Tourism
Lamy Bldg
491 Old Santa Fe Trail, Rm 117
Santa Fe, NM 87503
(505) 827-6465
(505) 827-6329, TDD

NEW YORK
Division of Tourism
One Commerce Plaza
Albany, NY 12245
(800) 225-5697
(518) 474-4116

NORTH CAROLINA
Dept of Tourism
430 N Salisbury St
Raleigh, NC 27611
(800) 847-4862

NORTH DAKOTA
Tourism Division
604 E Blvd
Bismarck, ND 58505
(800) 435-5663
(701) 224-2525

OHIO
Dept of Tourism and Travel
77 S High St, 29th Fl
Columbus, OH 43266
(800) 282-5393
(614) 486-8844
(614) 462-4951, TDD
(call collect)

OKLAHOMA
Tourism and Recreation
241 N Lincoln
500 Will Rogers Bldg
Oklahoma City, OK 73105
(405) 521-2406

OREGON
State Office of Tourism
1115 Commercial St NE
Salem, OR 97310-1001
(503) 378-6305

PENNSYLVANIA
Travel Dept
453 Forum Bldg
Harrisburg, PA 17120
(800) 847-4872
(800) 332-8338, TDD

PUERTO RICO
Division of Tourism
PO Box 4435
Old San Juan Station
San Juan, PR 00905
(809) 721-1712

RHODE ISLAND
Rhode Island
Dept of Economic Development
7 Jackson Walkway
Providence, RI 02903
(800) 556-2484
(401) 277-2601

SOUTH CAROLINA
Dept of Parks, Recreation and Tourism
1205 Pendleton St
Columbia, SC 29201
(800) 346-3634
(803) 734-0235

SOUTH DAKOTA
Chamber of Commerce
PO Box 747
Rapids City, SD 57709
(800) 487-3223
(605) 343-1744

TENNESSEE
Tennessee Tourist Development
PO Box 23170
Nashville, TN 37202-3170
(615) 741-2158
(615) 741-0691, TDD

Association for the Care of Children's Health
29th Annual Conference

May 22-25, 1994

Westin Harbour Castle Hotel ◌ Toronto, Canada

Conference Highlights:

Sunday, May 22

Opening of Exhibit Hall followed by Celebrating Parent/ Professional Partnerships Reception

Monday, May 23

Opening Plenary — Commemorating Victoria Day in Canada "Health Status of Children in the Industrialized World: Reforming Health Care"

Tuesday, May 24

4th Annual ACCH Corporate Breakfast and Plenary — "Macaroni at Midnight"

Tools for Pediatric Health Care in the '90s . . . and beyond

Wednesday, May 25

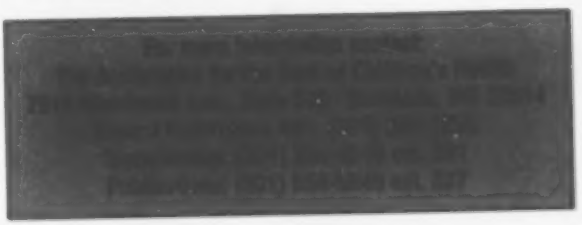
4th Annual Brazelton Lecture: with introductory remarks by Dr. T. Berry Brazelton: "Dreams, Schemes, and Flying Machines: The Children's Hospital's Vision, Strategy, and Perspective for Family-Centered Services"

President's Luncheon — "Top Hat and Tales in Your Tool Box: Storytelling as a 'Power' Tool Anyone Can Use"

Closing Plenary: "Tools for Pediatric Health Care in the '90s and BEYOND: Connecting with the Spiritual Aspects of Our Work" with dramatization of "The Goop-Ooze Story of Creation"

PLUS MUCH MORE FOR PARENTS & PROFESSIONALS:

1994 ACCH/NACHRI Capitol Hill Photo Exhibit: "Visions of Caring" ◌ **130 Concurrent Sessions** ◌ **95 Poster Sessions** ◌ **60 Exhibitors** ◌ **And great social events in an enchanting city!**



A heart sheltered by a roof, linked by another heart, to symbolize life and love in a home where one finds warmth, caring, security, togetherness, tolerance and acceptance — that is the symbolism conveyed by the emblem of the International Year of the Family 1994. The open design is meant to indicate continuity with a hint of uncertainty. The brushstroke, with its open line roof, completes an abstract symbol representing the complexity of the family.

The Association for the Care of Children's Health fully endorses and supports the goals and objectives of the Canada Committee for the International Year of the Family 1994 and accepts to be recognized as official partners of the said Committee.

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support

The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle #13

Travel Resources

TEXAS
Travel/Information Division
125 E 11th St
Austin, TX 78701-2483
(800) 452-9292
(512) 463-8586

UTAH
Travel Council
Council Hall, Capitol Hill
Salt Lake City, UT 84114
(801) 538-1030

VERMONT
Division of Vocational Rehabilitation
103 S Main St
Waterbury, VT 05671-2303
(802) 241-2186, V/TDD

VIRGINIA
The Opening Door
8049 Ormesby Ln
Woodford, VA 88580
(804) 633-6752

WASHINGTON
Dept of Commerce and Economic Development
Tourism and Travel Division
RSVP Volunteers
PO Box 42500
Olympia, WA 98504-2500
(206) 586-2088

WEST VIRGINIA
Division of Tourism, Parks and Recreation
State Capitol Complex
Bldg 6, Rm B564
Charleston, WV 25305
(800) 225-5982
(304) 348-2764

WISCONSIN
Wisconsin Travel Information Ctr
PO Box 7606
Madison, WI 53707-7606
(800) 372-2737
(608) 266-2161

WYOMING
Division of Tourism
I-25 at College Dr
Cheyenne, WY 82002
(800) 225-5996

CANADA

ALBERTA
Alberta Economic Development and Tourism
10155 102nd St
3rd Fl, Commerce Bldg
Edmonton, Alberta T5J 4L6
(800) 661-8888
(403) 427-43213

BRITISH COLUMBIA
Ministry of Tourism
The Parliament Bdlgs
in British Columbia
Victoria, BC V8V 1X4
(800) 663-6000

MANITOBA
Travel Manitoba
155 Carlton St, 7th Fl
Winnepeg, Manitoba R3C 3H8
(800) 665-0040
(204) 945-3777

NEW BRUNSWICK
Information unavailable

NEWFOUNDLAND
Dept of Tourism and Culture
PO Box 8730
St Johns, Newfoundland A1B RK2
(800) 563-6353
(709) 729-2830

NOVA SCOTIA
Nova Scotia Dept of Economic Development and Tourism
PO Box 456
Halifax, Nova Scotia B3J 2R5
(800) 565-0000, Canada
(800) 341-6096, USA
(902) 424-5014

ONTARIO
Ontario Tourism
111 Lisgar St
Ottawa, Ontario K2P 2L7
(613) 237-5150

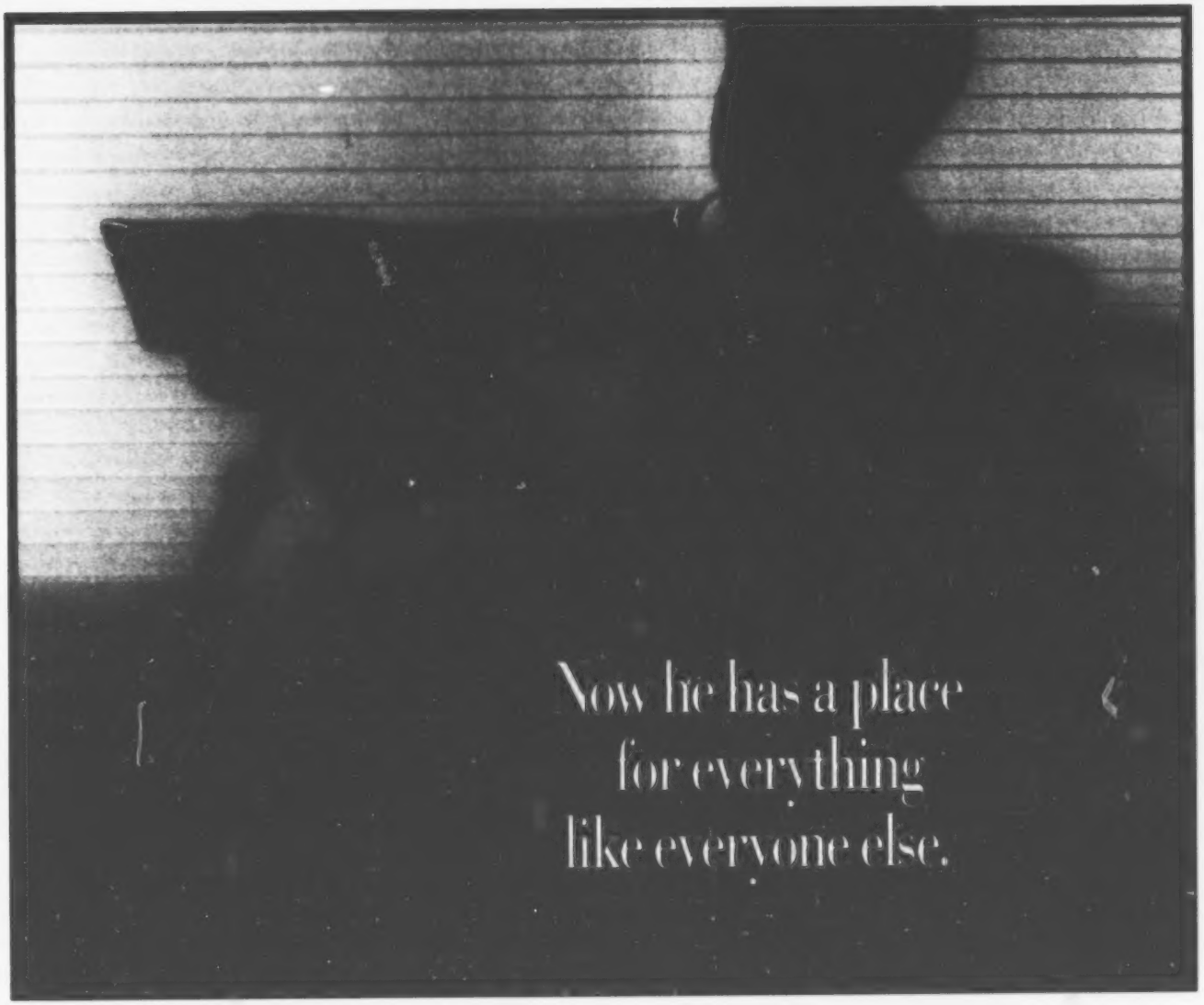
Ministry of Culture, Tourism and Recreation
Customer Sales and Service
77 Bloor St W, 9th Fl
Toronto, Ontario M7A 2R9
(800) 668-2746
(416) 314-7552
(416) 314-0944

QUEBEC
Direction de Communication
800 Tour de la Victoria
PO Box 125, Office 260
Montreal, Quebec H4Z 1C3
(514) 873-7977

Tourisme Quebec
PO Box 979
Montreal, Quebec H3C 2W3
(800)-363-7777

SASKATCHEWAN
Tourism Saskatchewan
1919 Saskatchewan Dr
Regina, Saskatchewan SP-3V7
(800) 667-7191
(306) 787-2300
(306) 777-5141, TDD

282



When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

1-800-4-MYDESC

RHAMDEC

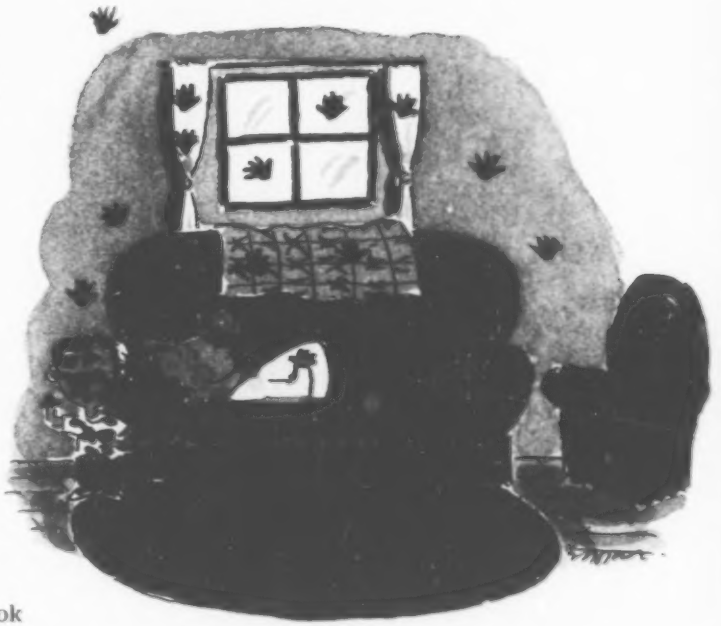
283

Rhamdec, Inc. • 46 Ellis Street, Mountain View, CA 94043-2240 • MYDESC is a trademark of Rhamdec, Inc.

Circle #103

Sense of Humor REQUIRED!

by Lynn Kimball Fay



It was an idyllic fall afternoon in Orlando in 1983. Life was good; God was in his heaven. Even the humidity was miraculously low. Then fate's fickle finger dropped the proverbial fly into the complacent ointment of our life. Our first child, Joshua, was diagnosed with Down syndrome. This same day—Black Monday—my husband, Dick, was laid off from his job as construction manager for a Florida-based firm.

Despite our conviction that the world had ended, the sun spitefully rose the next day and plopped us into the turbulent white-caps of readjustment. We began wildly treading water until, at last, we managed to bump up against a life-raft—half drowned, but definitely better swimmers. It took two years. If I seem to be talking in philosophic clichés, it is because we examined them all during the first few years of Josh's life.

Dick's new position took us from Orlando, to Nashville, to Indianapolis, then home to Romeo, Michigan, all within four years. Our travels also took us through many early intervention programs and parents' groups—all with diverse views on special education.

The opportunity to see so many different parental reactions and adjustments to having a child with a disability helped us chart our own course. We were not destined to become activists and advocates. Though we thank God that such people exist, we felt that if our entire family life revolved around Josh's "syndrome," we would be accentuating his differences rather than treating him like any other family member. We wanted as normal a life as possible. And we had added two more children—with their own needs—to our family. So, "life as usual" became our philosophy. Along with this perspective came a finely developed sense of humor. In fact, humor became a requisite for survival at our house. I believe our attitude resulted from a total acceptance of Josh. God made him as he is, so don't tell *me* God has no sense of humor!

PARENTING

Working to include Josh in school, religious and community programs has provided us with enough material for a sitcom. Many times, however, people have seen only tragedy in our experiences with Josh. In all honesty, I have to admit that Josh's antics were not always humorous at the time. But in retrospect, not only are Josh's escapades funny, we also delight in his cleverness. And we are *never* bored!

Josh's transgressions began to form a pattern over the years, so I have categorized them. They include errors of interior decoration, life and limb, hide and seek, fashion, etiquette and academic enlightenment.

Interior Design

Josh has always had an interest in interior design. "Trash-and-go" is his basic modus operandi, but he has

284

been known to use some unusual, creative art supplies. The only episode that can be mentioned here, however, resulted when old Dad fell asleep on the couch while Josh used some green stencil paint to great advantage. When it was all over, Josh looked like the Jolly Green Gremlin and his "country green" world included a three-foot diameter splotch on the carpet, and free-expression finger prints on curtains, chairs and even Great-Grandma's hand-made quilt!

Life and Limb

Josh's mistakes in this category definitely were not funny at the time. But after the fact, we had to laugh. At the same time, we made mental notes to prevent a recurrence. We remember the time Josh managed to open the car door just as Dad wheeled around a corner. A horrified Dad completed the turn with one hand firmly attached to Josh's drawers.

Then there was the time three-year-old Josh suddenly vanished from the Montessori school. After an exhaustive search of the building, the teachers saw Josh standing outside, grinning impishly at them through the front window and waiting for them to give chase.

I'll always remember the morning when I tiptoed out to get the paper in my pajamas... in January... in Michigan. Just as my fingers brushed the newspaper, I heard the door close—or rather *lock*—behind me! Once again, Josh gave me that infuriating grin through the front window but refused to let me in even though he knew full-well how to do it. Always resourceful, I managed to find a brick to use on the back-door window. Inside the back door was a landing before a full flight of stairs. Unfortunately, due to my anxiety, I underestimated my strength—the brick and the glass both made the bottom of the stairway.

Etiquette

Josh's manners can be extraordinary—in all senses of the word. His teachers will never forget the time he talked them into letting him sit down on the toilet while they made the mistake of standing in front of him. Or the time he sneaked up next to Uncle Rick at the dinner table, gave him a big hug, and then snatched the last piece of steak off his plate. Or the time he dropped that piece of chocolate cake into his dad's water glass.

Seven-year-old Joshua (center) spends a lazy summer afternoon with sister Hilary and younger brother John.

Then there was the time Grandpa took Josh and brother John to pick sister Hilary up from Sunday school. It was a lazy Sunday morning; Grandma and Grandpa were baby-sitting. Hilary was the only one to attend this Sunday. Sunday school started at 9:15 a.m., and Grandpa was supposed to pick her up before the 10:30 a.m. church service. When Hilary failed to come out of the church at the appointed time, Grandpa and the boys went in to investigate. Unfamiliar with the lay-out of our church, Grandpa—unshaven and, needless to say, inappropriately dressed—was quite a sight as he chased Josh down the center aisle of the church in the middle of the Sunday service!

Our favorite incident in the etiquette category, however, has to be one that occurred at Josh's public school Christmas pageant. He was seven years old and in the second-grade language-delayed program. We were very surprised that Josh stayed with his class on stage even though he spied us sitting in the audience. We watched with pride as he expertly played a bell in one song and a tambourine in another. For the last piece, the kids sang "Good Saint Nick." At one point in the carefully choreographed number, all the kids stretched out their arms in unison. Right on cue, Josh stretched his arms out as well—only along the way, he wiped his nose along the full length of his

A MOST ACCESSIBLE STORE

The Apple Computer Disability Solutions Store

Aisle 17 is a new kind of store, brimming with Macintosh solutions. For children and adults with disabilities. For rehabilitation professionals.

For you. Aisle 17 has been specifically designed to meet your needs. With the product bundles you told us to assemble. With the support you told us you want. With the convenience you told us you must have. And with special pricing available nowhere else. There's never been a store like Aisle 17, a place dedicated to computing without boundaries. Aisle 17. The power of personalized computing. Just a phone call away. The Apple Computer Disability Solutions Store. 1-800-600-7808

sleeve. We were amazed at how politely the audience ignored it.

Hide and Seek

In this category, Josh hides, and I seek. He particularly loves to throw things—crusts of bread behind the couch, my car keys out the tiniest of holes in the screen or laminated flashcards down the toilet. A little less amusing are the times he throws his glasses or shoes out the school bus window—something he still enjoys.

Perhaps the most memorable incident occurred when he accompanied his grandfather fishing and threw Granddad's $300 downrigger (a weight made of cast iron) off the fishing boat. Unfortunately, it was *not* attached to the line at the time.

Fashion

Josh has always had what one might term a sense of freedom when it comes to making a fashion statement. As far as Josh is concerned, the very *best* clothes are *no* clothes, and you never know when Josh may streak a dinner party. Sometimes he likes to wear his little brother's shirt, and *that's all*. He also gets very attached to certain clothes and will tear the house apart until he finds them—even if it means pulling out all the wet clothes from the washer and putting on the treasured garment, sopping wet!

Most distinctive, however—and I know the neighbors will agree—are the times when Josh races through the neighborhood… naked… in the winter… with his mother, in various stages of disarray, wading madly through snow drifts in pursuit. By the way, we have many special locks on all the doors—all of which Josh has learned to negotiate with the aid of a chair.

Academic Enlightenment

This is my favorite category since it is here that Josh displays the most ingenuity, creativity and initiative. I know I will never remember all the incidents that belong in this section, but several come to mind immediately.

Even when Josh had virtually no language skills, he knew, of course, how to say "no!" It was always expressed emphatically and with intense satisfaction. He pronounced it, however, like the Hollywood version of a German soldier—"Nein!"

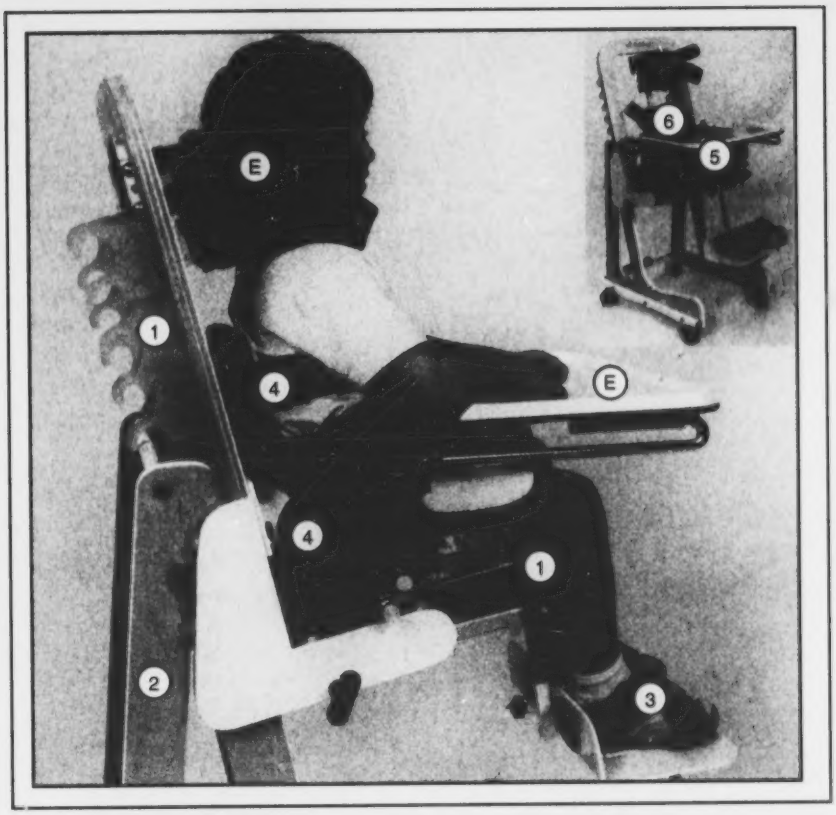
During this same period in Josh's life, we worked intensely on the development of expressive language skills. At the time, his vocabulary consisted of about six words. To our dismay, every time Grandma came to visit, she reinforced one rather off-color word. "Sh–t!"—said with such intensity and shameless enthusiasm that Josh never failed to notice—was one of her favorite expressions, and quickly became one of his. We spent many months, particularly in public, pretending he had said something else. "Sure Josh," we'd say, "*Sit* down if you want to!"

When Josh was about four, he finally learned to count to twenty. We were *really* proud of him. All those hours of hard work had finally paid off. He could read those numbers in any order, and counting was one of his favorite pastimes.

One night, all our friends had gathered in our home for a formal holiday dinner party. It had been a pleasant evening. The kids had cooperated, and chaos had been kept to a minimum. As we enjoyed a final cup of coffee around the big harvest table, Josh climbed up on my lap and gave me one of his big, sloppy kisses. As a lull in the conversation occurred, Josh pointed at my chest. "One! Two!" he counted proudly, and loudly. When the laughter subsided, and all eyes were wiped dry, my husband sweetly remarked that not only was Josh extraordinarily brilliant, but his eyesight must be much better than we had previously assumed! All in all, I couldn't be *too* upset. Hey, the kid was learning!

Lynn Kimball Fay is a freelance writer who has been published in Lady's Circle, Country Almanac *and* Byline. *She represents Romeo Community Schools on the Macomb Intermediate School District Special Education Parent Advisory Committee. Josh is now 10 years old, and is fully included in a second-grade classroom at his neighborhood school.*

288



#17 Positioning Aid Chair™

Back To Basics

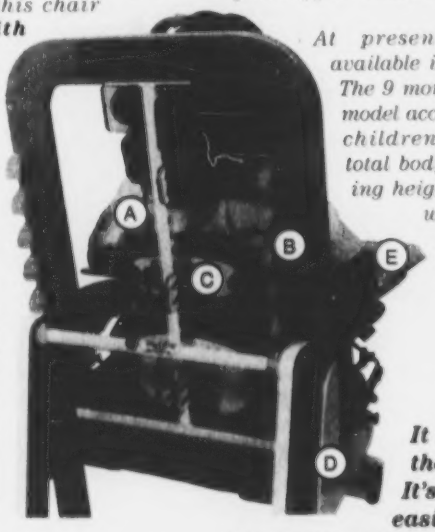
This Special Purpose chair's design originates from textbook seating principles that have been used and proven effective by therapists world wide. ***These principles, combined with our in-house rehab and design/ergonomic expertise, produce our unique Positioning Aid Chair™*** *(PAC). The PAC can be used for a variety of purposes (e.g., as a feeding/speech chair, floor sitter, classroom seating, etc.). Depending on the accessories used it can provide* ***exceptionally comfortable*** *full-body support for children with mild to severe central nervous system and neuromuscular disorders.*

The child size PAC is approximately 17" wide by 24" deep, 30-42" high. It is principally made out of laminated hardwood and plastics. It's average weight is 38 pounds. Included with each basic unit are the following: (1) Removable height and depth adjustable seat, (2) Mobile base with locking swivel casters, (3) Removable height and depth adjustable foot rest with foot positioning straps, (4) 45° hip and chest control belts, (5) Removable depth adjustable, leg wedge or pummel, (6) Washable slip covers over bidensity foam padding for the thoracic, lumbar, arm and seat pads.

Features Follow . . . Function

The basic ***PAC provides*** *a variety of features that make this chair* ***truly unique with respect to the posture support and utility it can provide.*** *(A) An open back design allows for easy access by attendants and allows for better fit. (B) Hook-ladder height adjustment makes changing from table to floor height, storage and/or travel a simple task* ***(see inset).*** *(C) All back/chest, head and neck support pads are mounted on a central column with arms that are adjustable in height, depth and angle. (D) Provides the all-important firm 90° seat back to seat pan angle while the entire seat is tilted back 105° to the floor.*

(E) ***Optional accessories*** *are available including: Trays of various types; Tray easels; Communication covers; Head, neck, and shoulder supports; *Belt cushions; *H-shaped chest supports; *Individual foot positioners; *Scolli/lateral chest supports; *Storage/ventilator bin; (* = not shown)*



. . . It's excellent support & adjustability make it ideal for home & school

Effective Benefits

Some of the PAC's consistently reported benefits include:

- *it's tilt and angle which allows for the use of gravity to help maintain a* ***more functional*** *posture*
- *the non-institutional looking design*
- *adaptability to children with a wide variety of postural problems*
- *improvement of eye/hand coordination, verbal and other skills*
- *reduced visual/postural imbalance, fatigue and stress*
- *convenient room to room movement of chair*
- *allows for the use of* ***existing*** *tables having a table to floor clearance of 19"-31" or can be used at floor level*
- *individual body part support without customization*

At present the PAC is available in one size only. The 9 month to 5 year old model accommodates most children 16" to 43" in total body length (standing height) 6-1/2" to 11" wide and up to 68 lbs. in weight.

The Bottom Line . . .

It works therapeutically. It's comparatively easier to adapt to different individuals, and activity settings. Plus it does all of this without looking like "ANOTHER" strange piece of equipment!

Consumer Care Products Inc.
P.O. Box 684, Sheboygan, WI USA 53082-0684
Telephone 414-459-8353; Fax 414-459-9078
est. 1978 © 1/94

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle #39

Exceptional Programs For Exceptional Children.

At St. Coletta Schools we believe life is what happens today. Our goal is to provide the best possible life experience for your exceptional child. Students here are not only preparing for tomorrow, they are living quality lives everyday. Founded in 1947, St. Coletta Schools offer a wide range of programs for children with mild to severe developmental disabilities. Twelve-month residential and day programs for ages 6-22.

- Extensive Vocational Training
- Functional Academics
- Community Skills Training
- Daily Living & Social Skills
- Adapted Phys. Ed. & Recreation Activity Program
- Special Olympics
- Behavior Management
- Physical & Occupational Therapy
- Speech Therapy
- Music, Art & Computers
- Prader-Willi Program

St. Coletta's
OF MASSACHUSETTS
John W. Shyne, Jr., President

Cardinal Cushing School & Training Center
400 Washington Street, Hanover, MA 02339
Braintree St. Coletta Day School
85 Washington Street, Braintree, MA 02184
Contact: Lynne Goyuk
Tel: (617) 826-6371
Fax: (617) 826-6474
Sponsored by
The Sisters of St. Francis of Assisi of Milwaukee, WI

Circle #73

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle #75

INCLUSION: Rhetoric and Reality

by Edwin W. Martin

GUEST EDITORIAL

A basic premise of P.L. 94-142, the Education for All Handicapped Children Act—now the Individuals with Disabilities Education Act (IDEA)—was that all children were entitled to an "appropriate" education. Judging appropriateness was to be an individual matter for each child and would be determined by an individual education planning process that would include parental participation. Decisions on placement could not be made solely on the basis of type of disability. When this issue actually arose, the government required that placement decisions involve multiple factors and be made on a child-by-child basis.

Another key premise was that children with disabilities be educated with non-disabled children—again, when appropriate. Congress, and the experts on whom they relied, did not expect that such placements would be appropriate for all; they also mandated that a range of placements be made available—resource rooms, special classes, special schools, hospitals or home tutoring.

Some would eliminate this individual placement process and educate all children in regular classrooms. They believe that all children would benefit from such placements and that schools can be made to deliver all necessary services. Others would go further; they would do away completely with the concept of "special education," replacing it with an improved regular education system.

Edwin W. Martin, Ph.D. is President and CEO of the National Center for Disability Services in Albertson, New York, and a member of the Editorial Advisory Board of Exceptional Parent. *From 1969–1981, he headed the federal government's special education programs as Director of the Bureau of Education for the Handicapped and as the nation's first Assistant Secretary for Special Education and Rehabilitation Services, U.S. Department of Education. Dr. Martin is shown here with President Jimmy Carter.*

Speaking with colleagues across the nation, I find that almost none agree with this position. While the Congress will study this issue carefully, I do not sense that they currently see a need for such change. IDEA does encourage inclusion, and the law should be implemented toward that end *if* it can be shown that the child benefits from inclusion—if inclusion is "appropriate."

Measuring Outcomes

Some inclusion advocates do not want the burden of demonstrating child benefit. That inclusion will be beneficial is an article of faith—not an issue for evaluation. At the same time, there is an equal burden on all who would offer other alternatives; we, too, must provide evidence of child benefit.

Unfortunately, educational systems—both regular and special education—have failed to provide even common-sense outcome measures. How many children go on to post-secondary training or college or get jobs? What type of jobs do they get, and how long do they hold them? Do graduates of special education programs live independently, have social relationships, feel positively about themselves?

My perspective on inclusion, and my recommendations for improving the education of children with disabilities, is closely linked to the measurement of "outcomes." As a parent, wouldn't *you* like to know how many graduates of a given special education or regular education program are employed or in post-secondary programs? While statistics cannot predict outcomes for any particular child, knowledge of a program's overall record would allow parents to consider the probability for success. Such information is not generally available. Instead, programs offer anecdotes that report the successes of specific children.

Is the Present System Working?

We have very little information about the value of special education programs, and the information we have

291

raises serious questions. The most comprehensive available data come from a study of about 8,000 high school students with various disabilities (Wagner, 1992, 1993). Conducted over a five-year period, the study provides information about post-secondary education, employment and other post-school outcomes for some of the study participants. I will present some illustrative data from this massive study to help me make some points:

1. *The present system, while working well for many, has many shortcomings, and the status quo does not seem acceptable.* For example, 60 percent of all special education students failed at least one regular-education high school course during their four-year or shorter enrollment (see Table I). The data indicate that children who fail classes are more likely to drop out of school, and common sense tells us they are likely to feel less self-confident. In fact, more than one-third of students with learning disabilities drop out or leave school prior to graduation.

2. *Children with disabilities who attend regular secondary schools do not receive a wide array of special services like therapies, life skills training or personal counseling.* Fifty-three percent of students with disabilities received none of these services. Only 14 percent received personal counseling. Even among children identified as emotionally or behaviorally disturbed, only about one-third received counseling.

3. *Only 16 percent of youth with disabilities out of school for three to five years attend any two- or four-year college, and most of these attend two-year colleges* (see Table II). Almost four times as many non-disabled youth attend college. Only four percent of youth with learning disabilities attend four-year colleges—fewer graduate. Highest enrollment in four-year college programs are found among students with visual and hearing impairments.

4. *The data raise the question of whether high school programs are aimed at the right outcomes.* Sixty percent of high school students with learning disabilities report that they wish to be competitively employed after graduation; only 28 percent plan to attend college. However, they are enrolled in programs with a very different emphasis—about 90 percent of their coursework is in regular academic courses.

Dr. Martin chats with Clinton Brown (left) and Rachna Vishnubhakat, students at the Henry Viscardi School, Albertson, New York.

Table I: Percentage of Youth With Disabilities Failing at Least One Regular Education High School Course*

Disability	Percentage
Learning Disability	65.1
Emotional Disturbance	77.4
Speech Impairment	56.4
Mental Retardation	48.5
Visual Impairment	53.5
Hard of Hearing	54.2
Deaf	44.1
Orthopedic Impairment	50.7
Other Health Impairment	65.7
Multiple Disabilities	50.0
All Conditions	**62.2**

**Adapted from* Youth in Transition: Trends in Post-School Outcomes, *SRI International, Menlo Park, CA.*

Where can we go from here?

My goal is to raise questions—not only about our current programs but about inclusion proposals and other future programming.

• To me, the data indicate that the prospects for inclusion are not encouraging—at least not now. These statistics suggest that the current system needs considerable improvement—more intensive programming and more services to children already mainstreamed. Even for children with learning disabilities—currently, the most frequently mainstreamed--the outcome data show high failure and drop-out rates; this suggests that the widespread assumption that such children are only "mildly disabled" is false. For further inclusion efforts to work, even more services and resources will be needed. Research and pilot programs must be focused on delivering positive results and identifying costs.

• The rate of failure in regular education programs has not been addressed sufficiently. Children who fail in their coursework are not being "appropri-

292

Table II: Attendance at Post-Secondary Schools by Youth With Disabilities*

	Percentage that attended:		
Disability	**Vocational School**	**2-year College**	**4-year College**
Learning Disability	19.0	13.7	4.4
Emotional Disturbance	15.4	10.1	4.2
Speech Impairment	16.4	25.4	13.3
Mental Retardation	9.6	3.6	–
Visual Impairment	15.6	27.5	33.4
Hard of Hearing	16.0	40.4	15.7
Deaf	22.5	33.2	22.1
Orthopedic Impairment	12.6	32.3	12.9
Other Health Impairment	33.9	28.4	21.9
Multiple Disabilities	0.7	7.9	2.2
Deaf/Blind	13.4	8.9	8.9
All Conditions	**15.9**	**11.8**	**4.2**

**Adapted from* Youth in Transition: Trends in Post-School Outcomes, *SRI International, Menlo Park, CA.*

ately" served. It is no victory for integration to enroll children in regular classes, and then have two-thirds fail at least one course.

• Deaf students—who are more likely to be educated in separate settings—are among those most likely to go to college. Many variables may be involved here, including the fact that the federal government supports two higher education programs for the deaf. Other data, however, also demonstrate considerable post-secondary success in schooling and employment by graduates of special schools (Rogan & Hartman, 1990; Liebert, et. al., 1990). My point is not to suggest more special schooling. Rather, we can study successful special programs to determine the factors accounting for their success, and whether those factors may be found or created in other settings.

• We have little information about the success of current programs, and we are unlikely to have evidence that new strategies are as good or better. This leaves us arguing philosophies and beliefs, not facts.

• The current systems are not working as well as we wish. Regular education admits that it is not doing a good job serving children with learning problems associated with poverty, immigration, minority status and language differences. Nothing suggests that it will do a better job educating children with disabilities. The status quo in special education is equally unacceptable. We need to measure and demonstrate improvement.

We should not eliminate alternatives that succeed. We should not simply adopt sweeping "inclusion" policies, however philosophically attractive, because children are likely to be hurt when sufficient services are not provided.

293

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle #25

PI BEAR™ (Physically Inconvenienced)
A Beary Special Friend

PI BEAR is a special friend that children can call their own. PI's three illustrated storybooks, which tell about his accident, recuperation, first day of school and other adventures with friends, can help disabled children understand their own feelings of fear and uncertainty. PI's friends also show others that your friends are friends, no matter what. PI BEAR and his wheelchair are approximately 14" tall. Dressed in a PI BEAR T-shirt, he comes with three story books (in chair backpack), a club membership certificate and a one-year warranty.

For more information, call: 1-800-467BEAR (2327)
Canada inquiries call: 613-258-0177.
VISA/MASTERCARD accepted.
Flexpay Available.

© 1993 PI BEAR CO. Patent pending

Circle #123

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle #26

We need a major, federally-funded demonstration program that will allow new models to be evaluated. The federal government has followed this strategy successfully with early childhood education. When federally-funded model programs, research, training grants and media development demonstrated that such programs were worthwhile, a policy of making early childhood programs universally available was adopted. A similar effort with regard to elementary and secondary education for children with disabilities could be equally successful.

Most importantly, neither parents nor professionals should accept rhetoric in place of data. Parents must insist on options, alternatives and a realistic say in how their children are educated while significant outcome data is accumulated to provide parents with informed choices.

References:

Liebert, D., Lutsky, L. & Gottlieb, A., 1990. Post secondary experiences of young adults with severe physical disabilities. *Exceptional Children*, 57:56-63.

Rogan, L.L. & Hartman, L.D., 1990. Adult outcomes of learning disabled students, 10 years after initial follow up. *Learning Disability Focus*, 5:91-102.

Wagner, M., 1992-1993. *National Longitudinal Transition Study of Special Education Students*, SRI International, Menlo Park, CA, various publications.

© 1991 RSI Patent Pending

The Baby Jogger®

Mobility and comfort combine for both parent and child! The ***Baby Jogger*** offers new models to suit a variety of special needs. Go anywhere with the ultimate all-terrain stroller. Travel over gravel, grass, curbs, even sand and snow with "The stroller for runners." Trips to the beach or park are easy with the smooth-rolling three wheel design. A variety of models available for children of all ages. **FREE BROCHURE.**

Racing Strollers Inc. P.O. Box 2189
Yakima, WA 98907 **(509)457-0925**
Safe, stable, endorsed by pediatricians.

Circle #177

Absolutely No Rinsing Required

Less than 5 minutes for a cleansing shampoo

No-Rinse Body Bath
Less than 10 minutes for a refreshing bath

No longer is bathing an ordeal

Call, write or FAX for free samples

N-R Laboratories

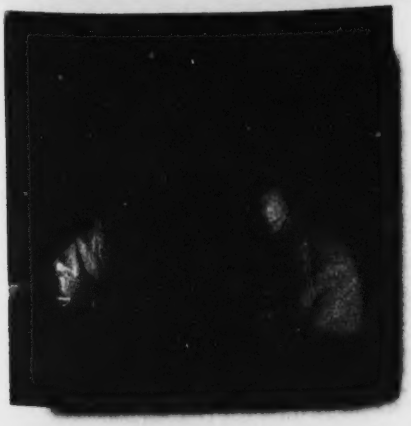
No-Rinse® Since 1948

900 E. Franklin St.,
Centerville, Ohio 45459
Toll free 1-800-223-9348
FAX 1-513-433-0779

Shampoo • Body Bath
The original liquid, non-rinsing hair and body cleansers
Ask your pharmacy or retailer for No-Rinse

Circle #1

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.



AND THEN BACK OUT AGAIN."

At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

P-CAP

CHRYSLER CORPORATION

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

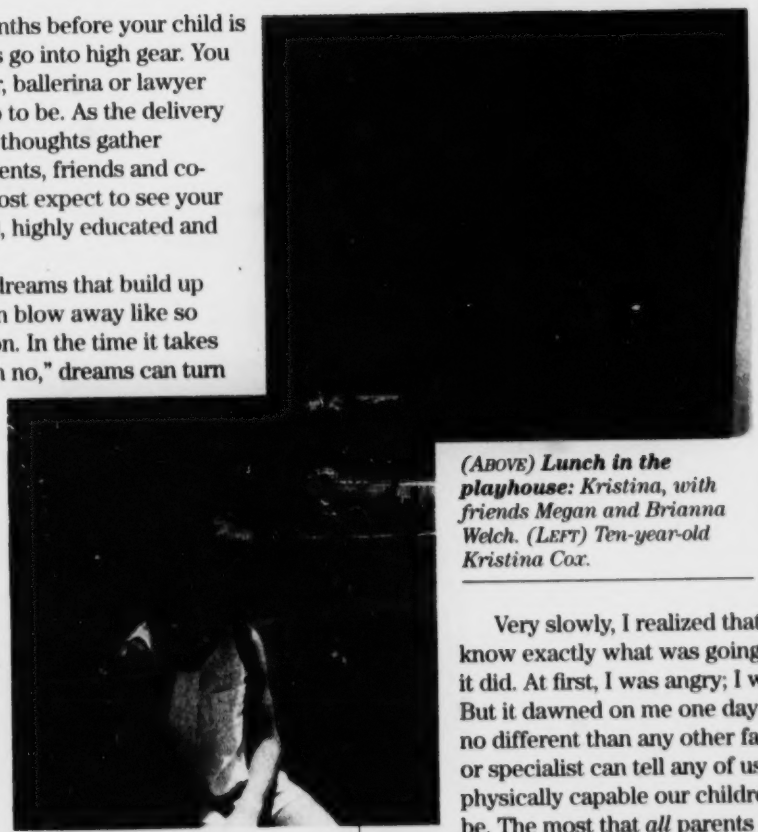
Circle #295

Dreams

by John Cox

It's those last few months before your child is born that the dreams go into high gear. You imagine the engineer, ballerina or lawyer your child will grow up to be. As the delivery date draws near, these thoughts gather momentum, fed by parents, friends and co-workers, until you almost expect to see your child born 18 years old, highly educated and physically attractive.

It's humbling how dreams that build up over so many years can blow away like so much air from a balloon. In the time it takes for a doctor to say, "Oh no," dreams can turn to nightmares and hopes to fears. Long-held thoughts of perfection melt away into short-term prayers and frantic thoughts: Will the baby be all right? What will we tell our parents? How did this happen? Why us? In a matter of moments, you have traded bar exams for brain scans, ballet shoes for blood tests, rock-solid normality for ground-breaking lunacy.



(Above) ***Lunch in the playhouse:*** *Kristina, with friends Megan and Brianna Welch. (Left) Ten-year-old Kristina Cox.*

I watched helplessly as my baby was poked and prodded by strangers who did not have the time to answer my questions or allay my fears. I coped with a day-to-day roller coaster ride of good news, then bad; hopeful signs, then puzzling questions. I found myself unable to dream, unable to see past the next doctor's visit or test—each time hoping that someone would be able to determine what was wrong or what would happen in the future. Instead, my frustration deepened as each test revealed only the need for more. Worse still, no prognosis for the future was forthcoming—everyone finally said that only time would tell.

Very slowly, I realized that I would never know exactly what was going to happen until it did. At first, I was angry; I wanted answers. But it dawned on me one day that I was really no different than any other father. No doctor or specialist can tell any of us how bright or physically capable our children are going to be. The most that *all* parents can do is to make the best of what is given to us. This new realization liberated my wife and me. We began to look toward the future again, and started doing things that would give us and our child choices.

New Dreams

I began to dream again. These were not the same dreams as before, but they were just as important. I dreamed of my daughter's first steps, and when they came, no parent was ever prouder. My wife and I dreamed of including her in a regular classroom at school, and after many battles, her first regular education teacher assured us that this was where she belonged.

I continue to dream of the future, of my daughter working, building meaningful relationships, and accomplishing great things for herself and others. I

John Cox is a sales supervisor in Los Angeles. His wife Shelley is the coordinator of the Exceptional Family Resource Center and works for the HOPE Infant Family Support Program in Oceanside, California. In addition to Kristina, they have two other children—seven-year-old Kimberly and four-year-old Travis. Kristina Cox, now 10 years old, was born with cerebral palsy and other significant challenges.

296

At the park: *John Cox enjoys an afternoon outing with two-year-old Kristina.*

know that she will never be a lawyer, doctor or ballerina, yet I dream about what she can become, cherishing each step she takes along the way.

All children are a gift to their parents, grandparents, teachers and everyone who comes into contact with them. And they all teach us something that we would not have learned without them. For me, it was to slow down so I could take pleasure in the details of my children's lives. I learned to take an active part in all my children's activities and cherish each of their accomplishments. I am richer for the experience of having a child with a disability. I would not wish it away.

A few years ago, I wondered what my daughter would have been like if she had not been born with a disability. I grieved for the loss of my "normal" life, somehow assuming that the one I had embarked on would not be as fulfilling. I don't think that way anymore. I am proud of my daughter's accomplishments, and like any father, I am looking forward to future accomplishments as well. I should not have worried as much as I did. Looking back, I see now that few others have been as blessed as I.

Fathers's Voices *is a regular feature of* EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth St., Bellevue WA 98008, (206) 282-1334. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda , MD.

The Very Best Europe Has To Offer!

At American Prices.

TRIAID
REHABILITATION PRODUCTS

301-759-3525

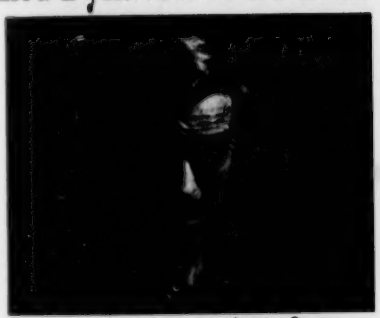
P.O. Box 1364 Cumberland, Maryland 21502

VISA-MasterCard Now Available

Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle #82

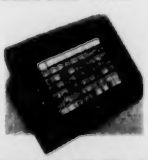
You Asked DynaVox To Do Even More...



"I want to communicate faster with my associates."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at **1-800-344-1778.**



We Hear You.

TECHNOLOGY INC.

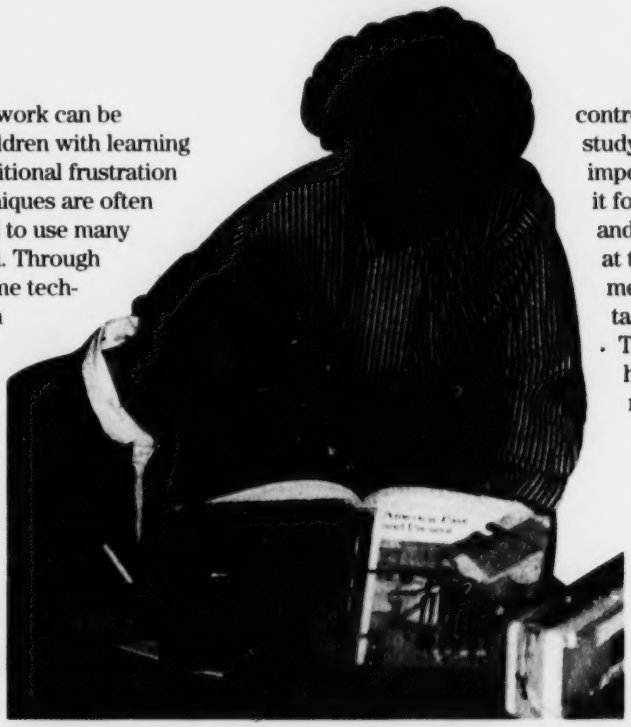
Circle #68

PARENTING

Listening to Learn

A tape recorder helps Eliot with his homework

by Elizabeth C. Mayer



Helping any child with homework can be difficult, but parents of children with learning disabilities experience additional frustration because traditional study techniques are often ineffective. These parents need to use many strategies to help their children. Through trial and error, I discovered some techniques that have helped my son become a more successful student. They also have made my life as a parent easier.

The label "learning disability" is an umbrella term that is used to describe many types of learning problems. Some of the techniques that worked for my child may not be as helpful to others. However, these tactics can be tried by any child and parent.

My 10-year-old son, Eliot, has weaknesses in both visual and auditory processing. He is also highly distractible. I reasoned that involving his eyes and ears in the learning process would allow him to assimilate more information, block unrelated distractions and improve his concentration.

Two years ago, we began experimenting with ways we might use a tape recorder to help him learn. We began with social studies, a subject where the sheer difficulty of reading an assignment left little time or energy for comprehension. His difficulties were reflected by extremely poor performance on weekly quizzes. I made audio tapes of each chapter in the textbook; he listened to them while reading along in the text. His comprehension and recall improved immediately and measurably—his score on the weekly quiz jumped to 100 percent! While this accomplishment was not always repeated, the following weeks showed that the dramatic improvement was not transitory. I began looking for other ways to use this "double-sensory" approach.

At this point, Eliot uses a tape recorder in almost every subject. Many of the techniques we use give him control over his own studying. This is an important bonus because it fosters independence and self-confidence and at the same time, frees me from some of the tasks of a home tutor. The greatest benefit is his growing sense of mastery and success.

Spelling

In a world of computers and "spell-checker" programs, some people consider spelling skills unimportant. But until spelling tests are abolished in school, Eliot is required to take one each week. Eliot already had a history of frustration and discouragement to overcome since he was often asked to spell words that he couldn't read. I wanted to make him feel that the effort he puts into studying his spelling list is worthwhile. I also wanted to foster his sense of being able to master this difficult task and, with effort, the next task as well.

The first step in studying for his weekly spelling test is for Eliot to read the words aloud to me. Once he can read them fluently, pronounce them correctly and understand their meanings, he makes an audio tape of the list, reading and spelling each word aloud. Over successive nights, he listens to the tape, writing each word as he hears himself spell it. This reinforces the word through three channels—auditory (he hears it), visual (he sees the word as he writes it) and motor (he writes the word). Usually, going through the list twice each night is enough.

After three nightly practice sessions, I give Eliot a "spelling test." If he is having trouble with only a few words, he makes a new tape of the words he missed. Sometimes, if the words are particularly difficult, he

LIFE

CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL® PEDIATRIC 3-WHEEL, RWD SCOOTER

The REGAL PEDIATRIC was anatomically designed to meet the special needs of your child. The REGAL PEDIATRIC offers these exclusive Bruno features: Custom Contoured, Adaptable Seating for superior lateral, thigh and lumbar support; 23 hardpoints in the seatback for the attachment of various support devices; tilt platform for exceptional legroom; E-Z-TILT™ filler with all driving adjustments selectable from the seated position and overall Proportional Sizing™ for your child's specific requirements.

SCOOTER-LIFT JR® AUTOTRUNK LIFT

At Bruno we help eliminate the burdensome task of transporting your child's mobility aid. We make **FOURTEEN DIFFERENT KINDS OF LIFTS** for nearly any brand of scooter or wheelchair, and they can be installed in cars, vans or trucks. Bruno can help your child get around easier and make traveling a truly enjoyable experience.

CURB-SIDER® SCOOTER & WHEELCHAIR LIFT

Bruno's unique, low cost, battery-powered **ELECTRA-RIDE** Stair-Way Elevator can help your child get up and down stairs, easily and comfortably. No special wiring is needed and **ELECTRA-RIDE** will operate even if there's a power outage. Seat-belt, two Remote Call-Sends, Adjustable Foot Plate with Safety Swing-Away, Full 45-90 Degree Swivel Seat and much more, including Control Panel Lock are standard. To give your child a journey's security and peace of mind...

ELECTRA-RIDE™ STAIRWAY ELEVATOR SYSTEM

BRUNO

WISCONSIN MANUFACTURER OF THE YEAR AWARD

SPECIAL AWARD INNOVATION 1988

MANUFACTURER OF THE YEAR 1991

BRUNO INDEPENDENT LIVING AIDS, INC.
1780 EXECUTIVE DRIVE, P.O. BOX 84
OCONOMOWOC, WISCONSIN 53066

and 1-800-882-8185 (outside of WI) or 1-414-567-4990

FAX 1-414-567-4341

also listens to the tape before falling asleep or while he is getting dressed in the morning.

Math

We used a similar technique when it was time to memorize multiplication tables. Eliot wrote the tables correctly in sentence form (e.g. "two times two equals four"). Then, he read them onto the audio tape. He practiced by listening to the tape and writing the examples as he heard them, mastering one table at a time.

Social Studies

The typical social studies curriculum requires that students read and digest the text, answer questions relating to the material and memorize facts—awesome tasks for some children! We have developed techniques that help Eliot perform all of these tasks.

First, we get or make a cassette recording of the social studies text so he can listen to the tapes while reading. Many textbooks—especially for grades five and higher—are available on tape through Recording for the Blind (20 Roszel Road, Princeton, NJ 08450, 609/452-0606). For a one-time fee of $37.50, a child who has a "print disability" becomes eligible to receive needed textbooks on tape. If no cassette exists, I make one. I found that it took less time than I would have imagined and certainly was worth the time invested.

Because Eliot has fine-motor problems, he finds writing time consuming and difficult. Now he often begins by answering homework questions directly onto a cassette tape. Once his ideas are refined and he is satisfied with his answers, he transcribes them, either writing longhand or using a word processor.

Eliot finds it helpful to make a study sheet of all the facts he needs to memorize for a unit or chapter test. He reads this information onto an audio tape. As he reads over his study sheet again, he listens to the audio track at the same time.

Recreational Reading

One important thing we can do for our children is to encourage them to become readers. This is an especially daunting task for parents and teachers of children with learning disabilities. These children view reading as hard, even painful work. The material they can read tends to be written below their intellectual and emotional levels and is not likely to be interesting enough to engage them.

Books on tape can solve this problem. Many prerecorded fiction and nonfiction works are available on cassette. When used in conjunction with the printed book, the child is able to hear the text while following the printed word. This type of reading becomes enjoyable because the audio track helps the child glide over difficult words and passages. Recorded books expose my son to literature on his intellectual level, let him have the same reading experience as his peers and increase his familiarity with literature of all types.

Novels, poetry, history, biographies and mysteries are available on cassette. Cassettes are available for free loan at most public libraries and can be purchased at most bookstores. We also have found several sources for renting books at reasonable rates—Recorded Books (800/638-1304) and Books on Tape (800/626-3333).

In addition, a person who has a disability that prevents the use of standard printed materials may be eligible to receive services from a free books-on-tape program administered by the Library of Congress. The National Library Service for the Blind and Physically Handicapped (NLS) supplies a special tape player and bi-monthly catalog describing a wide range of recorded books that are delivered and returned by postage-free mail. Eliot and I go through the catalogs together and he chooses titles which are age-appropriate but too difficult for him to read without assistance. When we receive a tape, we borrow the corresponding book from our local public library.

Eliot's interest in reading has increased. Rather than becoming dependent on tapes, he is starting to read more on his own.

Applications for the NLS program are available at some public libraries or can be obtained by calling the Library of Congress at (800) 424-8567. For a person who has a learning disability to receive NLS services, a doctor's signature is required.

Since Eliot started with this program, his interest in reading has increased. Rather than becoming dependent on tapes, he is starting to read more on his own. Some nights he reads, or reads and listens for half an hour or more—just for the pleasure of it! Nothing is more thrilling for me than when we are able to discuss a book he is reading or has just finished!

Use Your Imagination!

The tape recorder has other uses also. Tapes of old radio shows like *The Lone Ranger* and *Fibber McGee and Molly* are an enjoyable way to improve auditory comprehension. These tapes are available at most public libraries, some record stores and through mail-order companies such as Adventures in Cassettes (800/328-0108). When Eliot is working on a task that does not have a listening component, we've found that tapes of classical music provide a sort of "white noise" that blocks more distracting household noises.

The study methods and techniques for recreational reading described here work in our house, and I hope they will be helpful to you as well. Feel free to experi-

300

At Devereux...

a helping hand is just a phone call away

1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:

- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Locations: Arizona, California, Connecticut, Delaware, District of Columbia, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Tennessee, Texas

For information and assistance, contact National Referral Services 1-800-345-1292

Devereux

Since 1912

Circle #19

The people around him started spinning around and around in crazy circles. Jesse struggled desperately to find a familiar face among the swirling images, but everything looked distorted and strange. To Jesse, it felt like the whole world had turned upside-down. In reality, he was lost in a seizure.

For Jesse, seizures were an unavoidable part of living with multiple disabilities. At times, his reactions were so severe that he would bruise himself. After years of searching for a place where their son could get the help he needed to learn and grow, Jesse's parents found Heartspring.℠

At Heartspring, seizure management plays an integral part in the individualized programs we develop for each child who experiences seizures. Medication is the focus of seizure management. Heartspring strives to treat the whole child focusing not only on medical requirements, but also his educational needs. Therefore, a program may include occupational, physical and speech-language therapies, vocational training and other programs to help children learn to live independent, active lives.

Thirteen months after Jesse enrolled at Heartspring, his seizures were reduced from twice a day to less than once a month. He learned to participate freely in class, but also play a tuba and even enjoy riding a merry-go-round. His parents credit Heartspring with the balance their son has found.

For more information on the individualized programs we provide for children with multiple disabilities including seizures, call Heartspring.

HEARTSPRING℠
A LIFESKILLS LEARNING CENTER
2400 JARDINE DRIVE · WICHITA · KANSAS 67219-4699
316 · 262 · 8271 · 800 · 835 · 1043

Formerly the Institute of Logopedics

302

Circle #38

ment with ways to use books and cassettes to make the study process in your home easier and more successful and to open new avenues of enjoyment for your child. These tools are just that—tools to communicate, to receive information and master skills, and to understand and enjoy the world.

It is very important not to become discouraged—children with learning disabilities can and do learn. In the beginning, your child may be resistant to trying new ideas. Eliot does not want to be different from other children and does not want me to "baby" him. With determination and patience, I was able to convince him to try my ideas. Once he saw that he was able to achieve better results while spending less time studying, he quickly accepted the new study routines!

Elizabeth Mayer is a library media specialist in an elementary school in the Syosset Central School District on Long Island, New York, where she has worked with children with learning difficulties. She is married and has two sons.

"I'm flying" by Arsenia Levie, West Hartford, CT

WHAT'S HAPPENING

Department of Education Upholds Right to Privacy

A South Dakota family recently prevailed on a complaint filed with the U.S. Department of Education alleging a violation of the rights granted to students and their parents under the Family Educational Rights and Privacy Act (FERPA). The parents of a special education student charged that the family's privacy had been breached when the local school board disclosed financial information about their son's individualized education plan (IEP) to the media and general public without their written consent.

The family charged that since July 1991, the school board repeatedly violated their privacy rights by including personal details about their son in meeting minutes published in local newspapers. The minutes included the parents' names, the name and tuition rate of the child's out-of-state school, and the amounts of reimbursement payments made to the parents for travel expenses. In addition, board members made statements to the press and in a public meeting attended by more than 80 people, discussing confidential aspects of the child's IEP, including identifying information.

After the disclosures, many residents of the community blamed a long-planned property tax increase on the high cost of this child's education. The turbulent public reaction resulted in numerous stories about the controversy that appeared in the media across the state, while many members of the community ostracized and badgered the child's parents. Finally, the family filed a complaint with the U.S. Department of Education, alleging a violation of their FERPA rights.

The Department ordered the school board to refrain from publishing personally identifiable information from student education records in the meeting minutes or releasing such information without the parents' prior written consent. In its defense, the board maintained that South Dakota law required publishing meeting minutes and an outline of all money spent, including the names of recipients. However, the Department concluded that the state law conflicts with FERPA if it permits disclosure of education records without parental consent.

For information about FERPA:

• *Your Child's School Records: Questions & Answers About a Set of Rights for Parents and Students* is a booklet available from the Children's Defense Fund, P.O. Box 90500, Washington, DC 20090-0500, cost: $3.75.

• A free brochure entitled *Access to School Records* includes guidelines for enforcing parental rights. Send a self-addressed, stamped, business-size envelope to National Committee for Citizens in Education, 955 Massachusetts Ave., Cambridge, MA 02139.

Support Groups

• A new support group has been formed for families affected by **Alagille Syndrome,** a rare condition characterized by too few bile ducts in the liver. An informational brochure and quarterly newsletter is available. Contact: Alagille Syndrome Alliance, 10630 SW Garden Park Pl., Tigard, OR 97223, (503) 639-6217.

• The **X-Linked Myotubular Myopathy** Resource Group provides support and promotes the exchange of information among families and medical professionals. For more information, contact Pam and Gary Scoggin, 2413 Quaker Dr., Texas City, TX 77590, (409) 945-8569.

• A new support group has been formed for people affected by **Incontinentia Pigmenti,** a genetic disease of the skin, hair and teeth. For more information, contact Colleen Kidder, I.P. Support Network, 34929 Elm, Wayne, MI 48184, (313) 729-7912.

• **Von Hippel-Lindau (VHL) disease** is a genetic condition that causes tumors in the eyes, brain, spinal cord, kidneys and adrenal glands. It often goes undiagnosed, or is misdiagnosed as cancer. For more information, contact the VHL Family Alliance at their new toll-free number—(800) 767-4845—or at 171 Clinton Road, Brookline, MA 02146, (617) 232-5946.

IT'S SO EASY, IT'S CHILD'S PLAY!
ACCESSHOWER + ADJUSTEASE = CLEANING SOLUTION
An AdjustEase Washchair is safe, wet fun in the shower and bath—and at the beach or pool, too!
Plus, it's your free-wheeling, sensible back- and back saver!
Accesshower is a barrier-free, good-looking, easy-to-do, 1-day, no-plumber project!
It's an affordable bathtub replacement. And more— you can even take it with you when you move!
Get your family into their Accesshower™ by May 30 and really clean up.
Save 40% on your child's AdjustEase™ washchair!
AccessAble℠
ENVIRONMENTS + PRODUCTS FOR EVERY BODY!
1 800 285 2525
FOR MORE BATH PRODUCT INFO TODAY!
WE FILL THIRD-PARTY PURCHASES THROUGH YOUR APPROVED HOME HEALTH DEALER. JUST CALL US FIRST!
Circle #9

RECREATION

Cycling

Cycles come with one, two, three and four wheels. Some require a bent-over rider position; some allow leaning back in a recumbent position. Some cycles are hand powered; some are leg powered. Some cycles—tandem cycles—allow two or more people to cycle together. Bikes and trikes are made for the beach, the mountains and all terrains in between. Children and teens with physical, sensory or cognitive disabilities can use cycles for transportation and recreation.

Types of Cycles

Modified Leg-Powered Cycles: A number of accessories—described in detail in ABLEDATA Fact Sheet #19—allow commercially available leg-powered bicycles and tricycles to be adapted for various physical limitations. Supports, belts and wide bench-style seats may be useful for riders with poor balance or trunk control. Adapted hand brakes and gear-shifting mechanisms can be employed by individuals with the use of one arm.

People with limited hand grip or strength can use hand and wrist straps connected to the handlebars, or vertical hand grips, to help them maintain contact with the cycle's steering components. An adult three-wheeled cycle may be an alternative to the traditional bicycle for persons with poor balance but otherwise good leg strength and trunk control.

Small hand-driven tricycle, Rifton Equipment, Rifton, NY

Hand Cycles: Hand-powered cycles have made cycling accessible to individuals who do not have the leg strength to use traditional leg-powered cycles. Hand-powered cycles are available in numerous designs with various features. Some require the rider to pedal with the arms; others are propelled by pushing and pulling a handlebar lever.

Tandem Cycles: Tandem cycles are designed to carry two or more cyclists, with each cyclist contributing to the cycle's propulsion. Most tandem cycles are leg powered, but a few allow one cyclist to use leg power while the second uses hand power. Tandems come in bicycle-style models with two or more wheels configured in a line, and in tricycle-style three-wheel models. Tandem cycles are especially appropriate for riders who are visually impaired since they can rely on a sighted navigator to steer the bike.

Special Accessories

The traditional two- or three-wheeled cycle is powered by the rider's legs, and steered by the rider's hands. Braking may either be accomplished by use of hand brakes or back pedaling with the legs.

• ***"Strap-in" Accessories:*** For individuals who are lacking in trunk control or balance, there are a number of accessories—for use with both leg-powered and hand cycles—that can help them ride. Please note, however, that most involve strapping the rider to the cycling equipment. Should the cycle tip over, the rider may not have the opportunity or arm strength to break the fall or to fall clear. Appropriate supervision should be given to riders using one or more of these "strap-in" accessories.

Therapeutic tricycle, Viewpoint Manufacturing, Spanish Fork, UT

• ***Pedal Attachments:*** Foot pedal attachments keep a rider's feet on the pedals. The device generally takes the form of a platform or sandal that is secured to the cycle pedal and has velcro or buckle straps that go over the rider's foot.

• ***Torso/Back Supports:*** For individuals with poor balance or marginal trunk control, torso or back supports may allow them to ride a three-wheeled cycle. Torso supports provide a full-body lateral support system. Back supports provide a high backrest, but do not prevent the rider from leaning from side to side as do torso supports.

• ***Hip Pads and Harnesses:*** Hip pads

continued on page 65

CYCLES AND ACCESSORIES DIRECTORY

The following list of cycle and accessory manufacturers is designated by letter code—"C" for cycles; "A" for accessories. The listed manufacturers offer products for children and youth. See ABLEDATA Fact Sheet #19 for extensive information about manufacturers and their specific products.

Anthony Brothers
1945 S Rancho Santa Fe Rd
San Marcos, CA 92069-5195
(619) 744-4763 (C)

Brike International
20589 SW Elkhorn Ct
Tualatin, OR 97062
(800) 800-5828 (C)

CD Denison Orthopaedic Appliance
220 W 28th St
Baltimore, MD 21211
(410) 235-9645 (A)

Consumer Care Products
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353 (C, A)
See ad on page 37

Danmar Products
221 Jackson Industrial Dr
Ann Arbor, MI 48103
(800) 783-1998 (A)

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681 (A)
See ad on page 41

Flaghouse
150 N MacQuesten Pkwy
Mt Vernon, NY 10550
(914) 699-1900 (C, A)
See ad on page 24

Freedom Specialties
Box 83
Cleghorn, IA 51014
(712) 436-2666 (C)

GE Miller
540 Nepperham Ave
Yonkers, NY 10701
(800) 431-2924 (C, A)

continued on page 65

Children of Promise

"I want to thank The Center's staff for the foresight, persistence and expertise in executing perhaps the finest program for autistic children and adults in the nation."

The New England Center for Autism, Inc.

The New England Center for Autism is dedicated to providing the most caring, comprehensive, and innovative education available today to children with autism and mental retardation.

Our behaviorally oriented, community-based center, serving students aged 3 to adult, has revolutionized the way in which children with autism and developmental disabilities are cared for and educated. At admission, these students have severe behavioral problems including aggression, self-injurious behavior and hyperactivity. Half of our students have seizure disorders.

Our educational facility is located in Southboro, Massachusetts, with 12 attractive student homes in nearby neighborhoods. Our professional staff includes clinical psychologists, special educators, social workers, nurses and physicians. Appropriate students are welcomed from all over the U.S.

For more information, please contact Vincent Strully, Jr., Executive Director.

33 Turnpike Road • Southboro, MA 01772 • (508) 481-1015 • Just 20 miles west of Boston

Circle #171

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
(609) 346-3300 • FAX (609) 435-4223
Brochure or video available upon request.

"Accreditation with Commendation"
Joint Commission on Accreditation of Hospital Organizations
Member: National Association of Children's Hospitals and Related Institutions

Circle #85

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: CRI
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle #162

NEW PRODUCTS

TOBY TRACHEASAURUS THERAPY TOY

This dynamic dinosaur is designed to help children understand their tracheostomy and to make speech therapy more fun! Toby is a plush toy, and comes complete with his own Shiley tracheostomy tube flange, Passy-Muir speaking valve and Toby Tracheostomy tube tie. The Toby Tracheasaurus line also includes a Toby Puppet, exhalation kits, coloring books, stickers and speech therapy forms. **Voicing!,** Newport Beach, CA 92660.

Circle 179

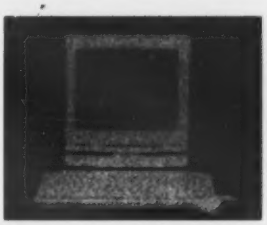
RIFTON UNIVERSAL CHAIR FRAME

The model K84 Universal Chair Frame is a modular seating system and torso support that can be used with conventional chairs and toilets. It features padded trunk supports, forearm prompts, handholds and rubber feet for stability. **Rifton Equipment,** Rifton, NY 12471-0901.

Circle 180

SCAN IT–SWITCH IT

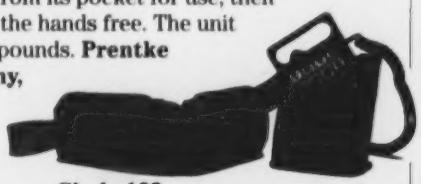
Teach horizontal and vertical scanning using a single switch or TouchWindow with this control switch training program game. Up to four can play on five levels of difficulty. Target object boxes can be displayed large or small. Players' names may be entered and record keeping is available. For use on Apple IIGS and Macintosh; a version for IBM and IBM-compatibles is in development. **UCLA/LAUSD Microcomputer Project,** Los Angeles, CA 90024.



Circle 181

WALKERTALKER™

Kids and teens on the go who use alternative speech devices: don't carry your communication board—wear it! The WalkerTalker is a speech output communication device housed in a waist belt. The communication board can be removed from its pocket for use, then returned to keep the hands free. The unit weighs only two pounds. **Prentke Romich Company,** Wooster, OH 44691.



Circle 182

KID-E-PLUS™

The Kid-E-Plus is a tilt-in-space mobility base and modular positioning system adjustable enough to accommodate growing children from infants to preteens. This stroller-like seating system disassembles for easier transport. A sun shade, pneumatic tires and anti-tippers are all standard equipment. Positioning accessories include an adjustable tray, head rests, hip supports, foot straps, lateral supports and an abduction block. **Kid-Kart, Inc.,** Belgrade, MT 59714.

Circle 183

THE BOBCAT

It goes up and down, it tilts in space and reclines, and it disassembles! It's the Bobcat! This powered wheelchair alternative is designed to allow kids to have face-to-face conversations with friends, play and maneuver about the classroom or house. Standard features include a powered elevating seat, self-jacking facility, front wheel drive, variable top speed to four mph, reduced or full speed in reverse, a warning sound in reverse at half-speed, joystick control and factory programmable electronics. The optional standing frame is interchangeable with the seat. **Advanced Rehabilitative Technologies,** Mason, MI 48854.

Circle 184

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284, V/TDD or (301) 587-1967, FAX.

306

Networking

Information from The National Parent Network on Disabilities

Hill Reception— An "Unequaled Success"

By Connie Hawkins

On Tuesday night, January 25, 1994, 500 parents and advocates for individuals with disabilities gathered and asked the congressional leadership to listen to our issues. The event was the first National Parent Network on Disabilities Congressional Reception to Honor Parents of Children with Disabilities; the issues included health care reform, family support, education reform and the reauthorization of the Individuals with Disabilities Education Act.

Twelve senators, thirty members of the House of Representatives and staff members from twenty additional Congressional offices attended the two-hour reception at the Senate Hart Office Building. Parent leaders from across the country had an opportunity to meet with legislators from their home states and other Congressional leaders to discuss disability-related topics.

Speakers included Senator Tom Harkin (D–IA), Senator Paul Wellstone (D–MN), Representative Major R. Owens (D–NY) and Maria Cuprill. Senator Harkin—Chairperson of the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education; and the Senate Labor and Human Resources Subcommittee on Disability Policy—addressed many issues of importance to parents. In his remarks, Senator Harkin emphasized family support and pledged to introduce family support legislation. He told the audience that he is aware of the need for family support because his mother and father were parents of a child with a disability. Senator Harkin has a brother who is deaf.

Senator Tom Harkin (IA) addresses parent leaders at the NPND Congressional Reception to Honor Parents of Children with Disabilities.

Senator Wellstone provided information on health care reform. He stressed that comprehensive reform of our health care system must include the needs of individuals with disabilities.

Representative Owens, Chairperson of the House Select Education and Civil Rights Subcommittee, said that our country needs to take a look at how money is spent. If Congress reprioritized the programs that received government allocation funding, he told the audience, the country would have adequate funding for health care reform and other disability-related programs.

Maria Cuprill, Staff Director of the House Select Education and Civil Rights Subcommittee, reemphasized her commitment to services for underserved and underrepresented families.

Patricia McGill Smith, Executive Director of the National Parent Network on Disabilities, termed the congressional reception an "unequaled success." She said, "Parents had the opportunity to let the Congressional leadership hear real issues from real families. And legislators listened."

NPND 1994 Annual Awards

The recipients of the NPND 1994 Awards are a distinguished group of leaders in disability and media:

- The **Kingsley Family** of Chappaqua, New York, received the *Leadership on Behalf of Families* award. Emily, Charles and Jason Kingsley are credited with a wide range of projects, including the work Emily did to promote children with disabilities on *Sesame Street* and Jason's new book, written with Mitchell Levitz (see page XX).
- **Christine Davis**, Executive Director of the Parents' Union for Public Schools in Philadelphia, received the *Exemplary Service to NPND* award for her outstanding work as a founding member. She has served as NPND treasurer for the past four years.

NPND honors Heumann: (left to right) Pam Stenberg, NPND secretary; Diana Cuthbertson, NPND President and Judith Heumann, Assistant Secretary for the Office of Special Education and Rehabilitative Services, U.S. Department of Education.

Rep. Major Owens (NY) enjoys the celebration with (from left) Diana Cuthbertson, NPND President; Maria Cuprill, Staff Director of the House Select Education and Civil Rights Subcommittee and Patricia Smith, NPND Executive Director.

• **Judith Heumann,** Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education, was presented an award for *Outstanding Educational Advocacy* for her work on behalf of students with disabilities. From her winning lawsuit against New York City that enabled her to teach to her involvement in writing Public Law 94-142—(now the Individuals with Disabilities Education Act), Judy has dedicated her life to bettering the lives of people with disabilities.

• **Joseph P. Shapiro,** staff reporter for *U. S. News and World Report,* was presented the *Outstanding Individual Contribution in the Media* award for his extraordinary reporting about people with disabilities. His book, *No Pity,* and his investigative report on special education entitled "Separate and Unequal" are just two examples of his fine work.

• ***U. S. News and World Report*** received the *Exemplary Leadership in Reporting on Disability Issues* award for its ongoing coverage of issues regarding people with disabilities, especially the article "Mothers of Invention."

• **Dr. Vince Hutchins,** longtime leader at the Maternal and Child Health Bureau, received an award for *Outstanding Service in Health Care and Family Issues,* and cited for his dedicated service in recognizing "family-centered" as the key adjective for describing services to children with disabilities.

The National Parent Network on Disabilities Board of Directors

Richard Burden
IN*SOURCE, South Bend, IN

Joanne Butts
Washington PAVE, Tacoma, WA, *Vice President*

Amparo Crespo DeCastro
Asociacion de Padres Por Bienestar de Niños, Impedidos de PR, Inc., Rio Piedras, PR

Connie Curtin
Vermont Parent Information Center, Winooski, VT

Diana Cuthbertson
Statewide Parent Advocacy Network (SPAN), Westfield, NJ, *President*

Kathryn Erickson
Pathfinder Services of North Dakota, Minot, ND

Joe Garcia
Touchstones, Seattle, WA

Paula Goldberg
PACER Center, Minneapolis, MN

Sweet Alice Harris
Parents of Watts, Los Angeles CA

Connie Hawkins
Exceptional Children's Assistance Center (ECAC), Davidson, NC, *Past President*

Bonnie Johnson
Arkansas Parent Support and Information Network, Little Rock, AR

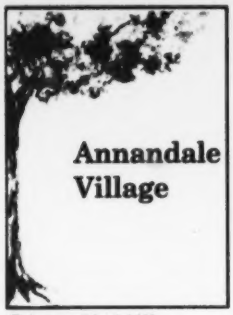
Joan Kilburn
MATRIX, A Parent Network & Resource Center, San Rafael, CA, *Treasurer*

Sue Pratt
CAUSE, Lansing, MI, *Vice President*

Pam Steneberg
Disability Rights Education & Defense Fund, Berkeley, CA, *Secretary*

Janet Vohs
Federation for Children with Special Needs, Boston, MA

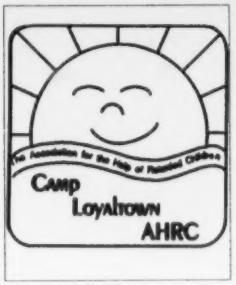
Patricia Smith
Executive Director



Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381



Camp Loyaltown provides a safe, fun-filled, enthusiastic & stimulating summer recreational vacation for mildly & moderately developmentally disabled children and young adults. Nestled in the Catskill Mts. at Hunter, NY, we offer classes in music, dance, drama, ceramics, wood working, sewing, cooking, swimming, athletics and team sports, recreation, crafts and nature.

Contact: Paul Cullen
Camp Loyaltown AHRC
189 Wheatley Rd.
Brookville, NY 11545
(516) 626-1007 x444

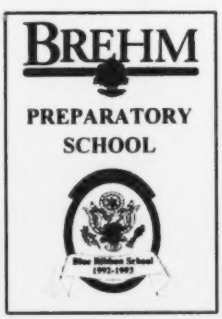
Bancroft
Where hopes take wing

INDIVIDUAL DAY & RESIDENTIAL PROGRAMS for children and adults with special needs including dev. disabilities, autism, head injury.
- A continuum of educational, vocational, & community living options.
- Complete clinical support services.
- Outpatient evaluation and remediation services.
- Neuropsychological testing.
- Vacation opportunities
- Programs in NJ and Maine.

Contact: **Bancroft**
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347

REAL CAMPING FOR THE MENTALLY HANDICAPPED. Activities carefully supervised-swimming, boating, riding, crafts. These are just some of the activities campers will enjoy. Founded in 1948 in the mountains of North Carolina.

Contact: Dan Norman or Betty Sharp
Camp Sky Ranch
Rte. 1, Box 540
Blowing Rock, NC 28605
(704) 264-8600

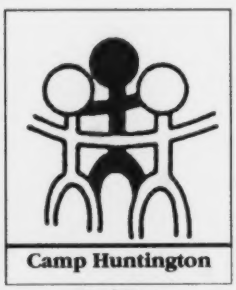


1993 BLUE RIBBON WINNER
Brehm Preparatory School is a Midwest boarding school designed to meet the academic, social, and emotional requirements of adolescents, age 12-21, with learning disabilities. Brehm offers specialized academic instruction, Orton training, speech and language therapy, and social skills guidance. Certified staff, family atmosphere, NCA accredited.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
[618] 457-0371

THE DUVALL HOME, EST. 1945. A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:
- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874
(800) 358-0450



33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

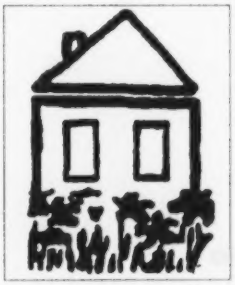
Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

THE LEARNING CLINIC
Country School and Residence enrolling children of all ages in a year-round program of specialized treatment for attention deficit and learning disability.
- small, selective and personal
- rural setting, pastures and animals
- tutorials in all subjects
- young apprentice program
- wilderness trips

The Learning Clinic, Inc.
P.O. Box 324
Brooklyn, CT 06234
(203) 928-5274
(203) 774-7471



RESPITE SERVICES provides short term residential care for children, adolescents and adults with disabilities. Respite Services gives a weekend break, vacation or help in times of illness or other crisis. Summer camp sessions are also available. Family style care and welcome in a country setting.

Contact: John & Pat Ryan
Respite Services
RRI Box 458
S. Gibson, PA 18842
(717) 756-2750
(717) 756-2870 Fax

SHEVET ACHIM in conjunction with YACHAD/NCSY is a new & exciting summer program in an Israeli Kibbutz. This four week program is designed specifically for high functioning Jewish young adults with developmental disabilities. Located in Kibbutz Ein Zurim, central Israel. Sabbath and Kosher dietary laws observed.

SHEVET ACHIM
63-67 108th Street
Forest Hills, New York 11375
(718) 997-1111 New York
(213) 651-5122 Los Angeles
(312) 764-4019 Chicago

TENNESSEE

TALL PINE CAMP
Exceptional Citizens
SINCE 1969

TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available.

Contact: Ron & Cammie Eydt
Tall Pine Camp
114 Tall Pine Circle
Tellico Plains, TN 37385
(615)261-2329/(615) 261-2138

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:
1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
9	Accessible Environments	51
	ACCH	29
170	ATT	C2
	Apple Computer	C1,3,34–35,C4
	Abilities Expo	64
6	Berkshire Meadows	63
173	Bethesda Lutheran	65
8	Bruno	47
90	Chrysler	43
11, 13	Columbia Medical	19, 30
109	Consumer Care Products	37
19	Devereux	49
172	Elwyn	14
25	Equipment Shop	41
26	Estate Planning	42
	Exceptional Parent Library	66, 67
27	Evergreen	38
174	Family Clubhouse	18
29	Flaghouse	24
30	Ford	7
153	Friendly Earth	62
	General Motors	16
39	HMS School	38
36	Haverich Ortho-Sport, Inc.	11
38	Heartspring	50
40	Homecare Products	5
43	Innovative Products	18
46	Kid-Kart	27
48	Laureate Learning	24
175	Martha Lloyd	62
169	Milani Foods	21
171	New England Center for Autism	53
55	New England Villages	62
56	Nu-Tech Health Products	20
1	N/R Labs	42
123	PI Bear	41
59	Permobil	13
177	Racing Strollers	42
103	Rhamdec	31
73	St. Coletta (MA)	38
74	St. Coletta (WI)	63
75	St. John's Villa	38
68	Sentient Systems	20
69	Snug Seat	C3
77	Stewart Home School	65
122	TMI	15
82	Triaid	45
85	Voorhees Pediatric	53
162	Willow River Farms	53
86	Woodbury Products	45

Books, Audio/Video & Educational Material

Conferences

Assistive Technology '94
A full day conference with over 100 exhibits of assistive technology equipment and services for people of all ages and with any kind of disability. Come see low- and high-tech equipment for use at work, in school, at home, and in recreation. Workshops and seminars on new technologies, advocacy, funding, and more. Registration fee $10 in advance; $15 at the door. For registration form and more information, call the Massachusetts Assistive Technology Partnership Center at (617) 735-7820 (Voice) or (617) 735-7301 TDD

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** P.O. Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Travel

Travelin' Talk
Network, newsletter, and directory for all travelers with disabilities. The only resource travelers should need to plan trips, discover true accessibility, or find help in case of difficulties away from home. International. Huge. Friendly. Inexpensive. Free brochures and copy of newsletter. Send SASE to **Travelin' Talk,** P.O. Box 3534, Clarksville, TN 37043, (615) 552-6670.

Books

Turtle Books
Provide a bridge of understanding for your child with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to **Jason & Nordic Publishers,** P.O. Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Attainment Company
Attainment Company's 1994 product guide of special education materials. Call or write for your free copy and see our latest items: Mac software, the Pocket Talker, board games, money skills materials. **Attainment Company,** P.O. Box 930160, Verona, WI 53593. Call (800) 327-4269.

Free—The NEW Special Needs Project Book Catalog The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. **Special Needs Project,** 3483 State St., Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog:
The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourette syndrome, Mental Retardation, Special Education and more. **Woodbine House**
Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: April 30, 1994

Expiration Date: July 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: April 30, 1994

Expiration Date: July 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

Schools, Camps, & Residences Directory

National Hotline Service

National Christian Resource Center on Mental Retardation
Bethesda Lutheran Home & Serv.
700 Hoffman Drive
Watertown, WI 53094
(800) 369-INFO
See ad on page 65

California

Southern California College of Optometry
2575 Yorba Linda Blvd.
Fullerton, CA 92631
(714) 449-7432
Comprehensive diagnostic and therapeutic vision care for visual impaired, exceptional and learning disabled children and adults.

Florida

Ralph J. Baudhuin School of Nova University
3375 SW 75th Avenue
Ft. Lauderdale, FL 33314
(305) 475-7324
A private non-profit day school for children with learning disabilities, attention deficit disorders, speech and language impairments, communication disorders and hearing impairments. Serves ages birth to eighth grade.

Georgia

Agape Village
3711 Agape Village Rd.
Macon, GA 31210
(912) 471-3700
Providing mentally disabled with 50 acre protected place to live, work in greenhouses and enjoy active life with supervision.

Annandale Village
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381
Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote well-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta.
See ad on page 57

Kansas

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 262-8271
Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Out-patient assessments, short-term treatment programs, and hearing center services are also offered.
See ad on page 50

Kentucky

The Stewart Home School
Box 20
Frankfort KY 40601
(502) 875-4664
Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure.
See ad on page 65

Massachusetts

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523
For children who are severely retarded, multiply disabled. Private, non-profit residential school located in the Berkshires.
See ad on page 63

Crystal Springs School
38 Narrows Rd. Box 372
(508) 644-3101, Ext. 328
Assonet, MA 02702
Established in 1953, Crystal Springs offers licensed home-like residences; and approved private school; full rehab. program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults, birth-22 yrs.

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-5597
Residential school for students who are developmentally disabled and require education or assistance in self-care, community living, adapted communication, mobility training or behavior control due to psychiatric/behavioral, medical or therapeutic needs. An intensive program is available for severe maladaptive or self-injurious behavior.
See ad on page 38

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.
See ad on page 57

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with develop. disabilities, behavior disorders age 3-22. Integrated preschool, inclusion svcs, staff intensive prog., functional activity based curr., supported employment in modern school and group homes.
See ad on page 53

New England Villages, Inc.
664 School Street
Pembroke, MA 02359
(617) 293-5461
Exceptional priv. community for MR adults offering a range of residential options, vocational, recreation and social opportunities.
See ad on page 62

St. Coletta's of Massachusetts, Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02339
(617) 826-6371
See ad on page 38

New Jersey

Bancroft
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347
See ad on page 57

New York

New York University—Pura-Educator Center
One Washington Place
New York, NY 10003
(212) 998-5800
Two year post-high school program for severely learning disabled young adults. Courses & supervised job training in human services, while emphasizing independent living skills. Graduates qualified to work with infants, toddlers, young children or senior citizens.

Ohio

St. John's Villa
P.O. Box 457
620 Roswell Rd. NW
Carrollton, OH 44615
(216) 627-9789
See ad on page 38

Pennsylvania

The Devereux Foundation
(800) 345-1292, Ext. 3045
(610) 964-3045
FAX (610) 971-4600
Residential, day and community-based treatment centers nationwide. Comprehensive services to individuals of all ages with emotional disturbances, developmental disabilities, mental retardation, dual diagnosis, autism, and post-head trauma.
See ad on page 49

Elwyn, Inc.
111 Elwyn Road
Elwyn, PA 19063-4699
(610) 891-2000/(800) 345-8111
Est. 1852, offering services from infant to adulthood. Education, rehabilitation, vocational training & placement. Day & residential.
See ad on page 14

N.M.S. School for Children with CP
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
See ad on page 38

Martha Lloyd Community Services
190 West Main Street
Troy, PA 16947
(717) 297-2185
See ad on page 62

Melmark, Inc.
Wayland Road
Berwyn, PA 19312
(610) 353-1726
A unique residential community near Valley Forge, Pa. Children/adolescents/adults receive special ed/adult day programs/OT/PT/speech-language /aquatic/pet/music therapy/ horsemanship. Self-help/safety skills and community involvement promote a more independent life style.

Rhode Island

The Groden Center, Inc.
86 Mount Hope Avenue
Providence, RI 02906
(401) 274-6310
Education and treatment for children & young adults w/autism & other developmental disabilities. Vocational programs; positive self-control techniques.

South Dakota

Children's Care Hospital and School
510 N. Cambell
Rapid City, SD 57701
(605) 342-4412
(800) 584-9298
Branch of Crippled Children's Hospital and School providing outreach and outpatient services for children through 21 who have disabilities or chronic illnesses. Our multi-disciplinary teams provide family-centered services based on each child's need.

Texas

Willow River Farms
P.O. Box 450
San Felipe, TX 77473
(409) 885-4121
See ad on page 53

Wisconsin

Chileda Habilitation Institute
1020 Mississippi Street
La Crosse, WI 54601
(608) 782-6480
FAX (608) 782-6481
Residential treatment for youths with severe mental & physical disabilities, closed head injuries & challenging behaviors.

St. Coletta School
W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330
Year-round res. prog. in academic instruction and prevocational training for MR/DD. Adult res. facility. Long term opportunity for care.
See ad on page 63

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

C & C Ford - Mercury
5th & Monroe streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/ used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Illinois

C & C Ford - Mercury
5th & Monroe streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Kentucky

C & C Ford - Mercury
5th & Monroe streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/ used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

New Hampshire

Ride-Away Corp.
51 Wentworth Ave.
Londonderry, NH 03053
(603) 437-4444
The most complete line of new & used adaptive equipment for vehicles in New England. Lifts, ramps,wheelchair securements, new/used vans, trade-ins, financing available. 24 hours everyday. Service, healthcare professionals on staff.

New Jersey

Arcola Mobility
51 Kero Road
Carlstadt, NJ 07072
(201) 507-8500
(800)ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

C & C Ford - Mercury
5th & Monroe streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/ used, lifts, drop floor, raised roof, lock downs, driving equip. NMEDA member. Owned by person with a disability.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tennessee

C & C Ford - Mercury
5th & Monroe streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

BEAT THE HEAT!
- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927
Made in USA Pat. 5168889 *Providing Comfort to Those Who Want It!*

Superior Quality

Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day and residential programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources.

There are five programs for women (from semi-independent to highly structured) including one specifically designed for mature women. **A new community-based program for men is now available.**

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

MARTHA LLOYD COMMUNITY SERVICES

For Information Call
(717) 297-2185
or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947

Circle number 175

Marketplace

Bicycle Trailer

Blue Sky Cycle Carts
P.O. Box 5788
Bend, OR 97708
(503) 383-7109
Enjoy cycling with the whole family. We offer customized bicycle trailers adapted to carry children & adults with special needs.

Catalogs

Anteon Toys and Products
232 SE Oak St Suite 103
Portland, OR 97214
(800) 826-8664/(503) 233-1680
Assortment of colorful toys, one piece underwear, hand-made dolls, educational books, diapers and more! Call toll free for catalog.

M & C Company
P.O. Box 4107
Schenectady, NY 12304-4107
(518) 357-2808
Personalized children's books are fun, exciting and encourage reading. Great Gifts for all occasions. All time favorite titles. Free brochures.

Cribs & Youth Beds

HARD Manufacturing Co.,Inc
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

Dowd Rental & Sales
100 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been servicing the area since 1930. For personal service and quality equipment and further information call Dowd Rental & Sales, Inc.

Loyal LaPlante Supply Co.
6702 E. 11th St.
Tulsa, OK 74112
(918) 836-6301
Custom seating. Check Marc certified repairs. Authorized Check Marc Repair Center. We carry most products & advertised in this magazine.

Rehabco
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in children's mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Advent Medical/Ride-Away
51 Wentworth Ave.
Londonderry, NH 03053
(603) 437-4444
Advent Medical specializes in all types of rehabilitation & mobility equipment for your child. Nurse & therapist on staff for any positioning issues. Dealers of all major brands of equipment. Skilled technicians, 24 hour everyday service. Huge list of references available.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35-75 lbs. $31.95/ea (96). Free Delivery. Also - Depend, Serenity other items. Manufacturer's coupons accepted. Free Catalog.

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
(800) 228-2766
We carry a full line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify care givers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog.

Resources

LINCS-SIG C/O PHP,
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Comfortable. Quiet. Affordable. Leakproof.

Just A Few Reasons Why You Must Try The Ultimate In Cloth Diapers

from the Friendly Earth Co.

★ Sizes newborn to adult ★

Are you throwing money away on disposables? The Friendly Earth Company has the perfect answer with the highest-quality cloth diaper you can buy anywhere.

Leakproof Cloth Diaper

Our revolutionary design is leakproof — the gentle elastic around the legs and waist offer a perfect fit. With 6 plush layers of 100% natural cotton on the inside and waterproof nylon on the outside, they're amazingly comfortable. They feature the ultimate in convenience with an innovative all-in-one design that fastens with either soft velcro closures or durable plastic snaps. No pins or diaper covers needed. Plus, they're ultra absorbent so no extra padding is necessary.

Best of all, our diapers mean incredible savings for you because they're washable and can be used for years. Plus, they're environmentally friendly.

Order Your Sample Today

Call and order your sample diaper today. If you're not 100% satisfied, simply return it within 30 days for a full refund.

Friendly Earth Company, Inc.
Specializing in quality incontinent products

1-800-358-2128

MasterCard Visa

Circle number 153

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages Inc.
A Model, Supportive Community For Mentally Retarded Adults
664EP School Street, Pembroke, MA 02359 (617) 293-5461

Circle number 55

Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Associations with leading specialists and major medical centers

Affiliation with SUNY

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

Circle #6

Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Colleta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills, personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

In A World Where Love Is Sometimes In Short Supply

We Have It In Abundance

1904 1994

NINETY YEARS

St. Coletta School

W4955 Highway 18
Jefferson, Wisconsin 53549

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.

Circle #74

REACH FOR THE STARS

ABILITIES EXPO® '94

New Jersey & California

The #1 Show of Products and Services for People with Disabilities

Opportunities to try and buy on the Show floor

One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-Wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

Longest running show of its kind in the U.S.

Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO in a city near you:

ABILITIES EXPO EAST
Edison, NJ
Raritan Expo Center
April 15–17, 1994

ABILITIES EXPO WEST
Anaheim, CA
Anaheim Convention Center
May 20–22, 1994

For more information on attending please call 203/256-4700.

SAVE ONE DOLLAR • SAVE ONE DOLLAR

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. *Name and address must be completed to validate coupon.*

Name _____

Address _____

City _____ ***State*** _____ ***Zip*** _____

Telephone (____) _____ – _____ ***CA/NJ94 J***

ABILITIES EXPO — *New Jersey* — Produced by Expocon Management Associates, Inc. and RCW Productions Inc. — *California* — ABILITIES EXPO

Cycling *continued from page 52*

for lateral waist support and shoulder and leg harnesses may be added to a torso or a back support.

• ***Modified Seats and Seat Accessories*** may be used to provide extra support or maintain knee abduction. Pressure sores—from extended periods of sitting on an insufficiently padded seat—may be another concern. Most standard seats—even on adapted cycles—do not have proper pressure relief seats. However, many will accommodate a wheelchair seat cushion. Another option for pressure relief during long bike rides may be the Jay Protector™ manufactured by Jay Medical of Boulder, CO. The Jay Protector is a minimally-sized fluid/foam cushion for children and adults that straps around the user's legs and waist to stay in place regardless of the user's movements.

• ***Adapted Handlebars and Handlebar Accessories***

• ***Protective Helmets:*** As with all sports equipment and in all recreational activities, safety is of the utmost importance. Protective helmets are recommended for all riders, and required by law for children.

Continued from page 52

Haverich Ortho-Sport
67 Emerald St
Keene, NH 03431
(603) 358-0438 (C, A)
See ad on page 11

JA Preston
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277 (C, A)

Jay Medical
PO Box 18656
Boulder, CO 80308-8656
(800) 648-8282 (A)

New Dimensions Design
90127 W Demming Rd
Elmira, OR 97437
(503) 935-3162 (C)

Palmer Industries
PO Box 707, Union Station
Endicott, NY 13760
(800) 847-1304 (C, A)

Patroni Machine & Design
9005 Amherst Ave
Margate, NJ 08402
(609) 823-8121 (C)

PCA Industries
5642 Natural Bridge
St Louis, MO 63120
(800) 727-8180 (C, A)

Quantum Leap
974 Pinson Blvd
Rockledge, FL 32955
(407) 631-8703 (C)

Quickie Designs/Shadow Products
20264 84th Ave S
Kent, WA 98032-1224
(800) 342-1579 (C)

Rifton Equipment
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866 (C)

Rock N'Roll Fun Machines
3405 69th Dr
Lubbock, TX 79413
(800) 654-9664 (C)

Specially Customized Bicycles
c/o John Van Note
PO Box 116
Englewood, FL 34295-0116
(813) 475-6646 (C)

Top End by Action
4501 63rd Circle N
Pinellas Park, FL 34665
(800) 532-8677 (C)

TRI KING
10 Drake Terrace
Prospect Heights, IL 60070
(708) 537-6032 (C)

Triaid
3 Commerce Dr
Cumberland, MD 21502
(301) 759-3525 (C)
See ad on page 45

Therapeutic Recreation Systems
Ste 3, 1280 28th St
Boulder, CO 80303-1797
(800) 621-8385 (A)

Viewpoint Manufacturing
PO Box 108
Spanish Fork, UT 84660
(801) 798-0181 (C)

This article was adapted from information contained in ABLEDATA Fact Sheet #19, written by Alynne Landers, M.I.M., ABLEDATA Program Specialist. Individual fact sheets are available free from ABLEDATA, a database of more than 19,000 products for people with disabilities. Most ABLEDATA publications are available in a variety of accessible formats, including large print, Braille, cassette, and computer diskette. Contact: ABLEDATA, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319. (800) 227-0216, V/TDD or (301) 588-9284, V/TDD. Fact sheets may also be downloaded 24 hours a day from ABLE INFORM, the free ABLEDATA electronic bulletin board system—(301) 589-3563, 1200–9600 baud, N-8-1.

Did I Hear You Say Help?

National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

☐ Are you looking for appropriate services for yourself, your family member or client?

☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline 1-800-369-INFO.

We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle number 173

Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Circle number 77

EXCEPTIONAL PARENT *Library*

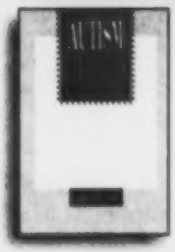
You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER

HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder
L. ADKINS & J CADY

Information about typical behavior characteristics; offers suggestions on how to foster the development of appropriate behavior.
PE040AD **$5.00**

AUTISM



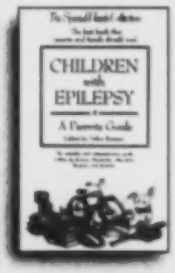
AUTISM
Information and Resources for Parents, Families, and Professionals
R. SIMPSON & P. ZIONTS
Resources book, presented in a question-and-answer format.
PE043OD **$24.00**

CHILDREN WITH AUTISM
A Parents' Guide
EDITED BY MICHAEL POWERS
A complete introduction to autism answers, questions, and gives hope to parents coping with this perplexing disorder.
WB017OD **$14.95**

WHEN SNOW TURNS TO RAIN: ***One Family's Struggle to Solve the Riddle of Autism***
CRAIG SCHULZE
A father's personal account. From birth through eight years; Schulze describes his son's transformation from a happy toddler to a progressively disconnected child.
WB029AH **$14.95**

DISABILITY, GENERAL

CAN'T YOUR CHILD SEE?
A Guide for Parents of Visually Impaired Children
E. SCOTT, H. JAN & R. FREEMAN
Practical guidelines for helping visually impaired children reach their full potential
PE041OD **$23.00**



CHILDREN WITH EPILEPSY
A Parents' Guide
EDITED BY HELEN REISNER
Chapters on diagnosis, medications, daily care, family life, advocacy, and special education.
WB019OD **$14.95**

DISABLED, FEMALE, AND PROUD! ***Stories of Ten Women with Disabilities***
HARILYN ROUSSO
Offers young women with disabilities empowering role models.
GW003EP **$12.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services.***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals
EP001EP **$14.95**

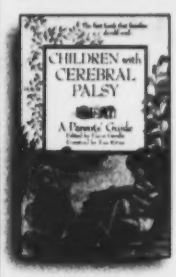
NOBODY'S PERFECT
Living & Growing with Children Who Have Special Needs
NANCY B. MILLER
Offers parents the strategies and emotional support to create a harmonious daily life and improved communication with family, relatives and professionals.
PB052OD **$21.00**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

PLANNING FOR THE FUTURE
Providing Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP024OD **$24.95**

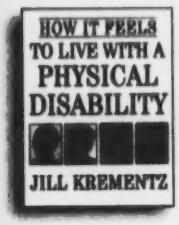
TROUBLE WITH SCHOOL
A Family Story About Learning Disabilities
ALLISON & KATHRYN DUNN
Book takes a clear look at the warning signs and common problems associated with LD.
WB028LD **$9.95**

DISABILITY, PHYSICAL



CHILDREN WITH CEREBRAL PALSY
A Parent's Guide
EDITED BY ELAINE GERALIS
About CP and how it will affect a child and family. Written by doctors, therapists, educators, and parents
WB012PD **$14.95**

COPING WITH CEREBRAL PALSY
Answers to Questions Parents Often Ask
JAY SCHLEICHKORN
Provides answers to more than 300 questions that have been carefully researched.
PE037PD **$24.00**



How it Feels to Live with a Physical Disability

Jill Krementz

Inspiring gift of hope from 12 children ranging in age from six to sixteen. Captured in text and photos, children tell their own stories and speak in candor.

SS014PD **$18.00**

Teaching the Young Child with Motor Delays: *A Guide for Parents and Professionals*

M. Hanson & S. Harris

Provides information to parents on how motor development influences other areas of development.

PE049PD **$27.00**

The Wheelchair Traveler

Douglas Annand

Information for the traveler with a disability. Accessibility ratings of hotels/motels in the U.S., Canada and Mexico. Although written for adults, it provides helpful info for parents.

WT015PD **$20.00**

EDUCATION

The Language of Toys *Teaching Communication Skills to Special-Needs Children*

S. Schwartz & J. Miller

Teaches parents how to improve their child's communication skills at home with, fun, easy-to-follow exercises.

WB0200D **$14.95**

You, Your Child and "Special" Education *A Guide to Making the System Work*

Barbara Coyne Cutler

Shows parents how to obtain the educational services their child rightfully deserves.

PB0530D **$22.00**

INJURY

When Your Child Goes To School After An Injury

Marilyn Lash

Issues parents need to confront about their child's future schooling, health care and social needs.

EP006ML **$5.00**

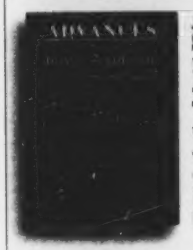
When Your Child is Seriously Injured: *The Emotional Impact on Families*

Marilyn Lash

Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.

EP005ML **$2.00**

MENTAL RETARDATION



Advances in Down Syndrome

Edited by V. Dmitriev & P. Oelwein

Twenty experts contribute their recent research, experience, and thoughts on future directions for children with Down syndrome.

PE045DS **$31.00**

The Child Who Never Grew

Pearl Buck

Brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation

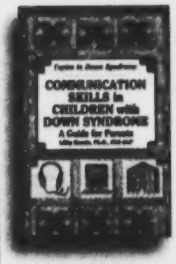
WB008MR **$14.95**

Children with Mental Retardation *A Parents' Guide*

Edited by Romayne Smith

Guide to everything parents need to know about raising their child and meeting their varied medical, therapeutic, and educational needs.

WB007MR **$14.95**



Communication Skills in Children with Down Syndrome *A Guide for Parents*

Libby Kumin

Parents learn how communication skills progress from infancy through the early teenage years.

WB031DS **$14.95**

Count Us In *Growing Up with Down Syndrome*

J. Kingsley & M. Levitz

The authors share their innermost thoughts, feelings, hopes and dreams and their lifelong friendship.

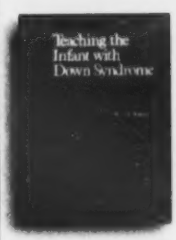
HB073DS **$9.95**

A Parent's Guide to Down Syndrome *Toward A Brighter Future*

Siegfried M. Pueschel

Thorough overview of Down syndrome, to guide parents through the life span of their child.

PB051DS **$20.00**



Teaching the Infant with Down Syndrome *A Guide for Parent and Professionals*

Marci Hanson

Expanded thoroughly updated, written specifically for the parent of a Down syndrome infants, step-by-step guide.

PE048DS **$27.00**

Mail to: **Exceptional Parent,** Dept. EP9404, P.O. Box 8045, Brick, N.J. 08723

Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: ____-____-____-____ Exp. Date ____/____

Signature _____

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

CHILDREN'S PAGE

The Golden Girls: *(from left) Lauren, Jana and Lindsay Golden.*

HAVING A SISTER WITH A DISABILITY

by Lindsay Golden

Hi! My name is Lindsay. I have two sisters. One is named Lauren and the other is named Jana. Jana is seven years old. Jana has a disability. She has a syndrome called Rubinstein-Taybi. Jana learns slowly and grows slowly. Her face is small and her nose is flat. But that doesn't bother me at all; I still love her.

The thing that does bother me is when people make fun of me for having a sister with a disability. I don't know why it bothers me though.

My sister might look sweet and friendly, but if you have to live with her she's a big, fat pain! What I mean is that when I'm not around or nobody is watching her, Jana will go into my room and mess it all up. It's a real big mess. The worst part about it is that my mom makes *me* clean it up—not Jana. My mom says Jana doesn't understand. Yeah, right!

Jana goes to Coventry Elementary School. She has a special class. This year Jana gets to spend one hour a day with the regular kindergarten class. I'm proud of her!

Jana's favorite things are corn, ketchup, horses, swimming, McDonald's, basketball, hula hoops and smiling.

I wish that people would accept my sister the way she is.

Lindsay Golden—now 11 years old and in fifth grade—lives with her family in Yorktown, Virginia, and attends Mount Vernon Elementary school. Her father, Mike, is an F-16 pilot and squadron commander for the 4525 Combat Applications Squadron at Langley Air Force Base. Lindsay's mother, Julie, has a teaching degree, owns her own business and is in training to become a child advocate for children with special needs. Lauren is ten and a fourth grader. Jana, now eight years old, is included in a first grade classroom at Dare Elementary school.

NEW!

FOR CHILDREN FROM 20 TO 105 LBS.

© 1993 All Rights Reserved Snug Seat®, Inc.

Let Our **GORILLA** Carry Your Most Valuable Possession!

We named our new car seat the GORILLA because it's stronger than any child restraint device on the market. The GORILLA provides comfort and support for children from 20 to 105 lbs.

The GORILLA's unique fully adjustable headrest provides stable head support, and our innovative pad system and seat extension kit enable the seating area to incrementally grow from 8" x 8" to 14" x 14", ensuring many years of use. The GORILLA also fits into our ROADRUNNER Mobility Base.

1-800-336-7684

Fax 1-704-847-9577

In Canada 1-800-667-3422

THE GORILLA Seat

BY SNUG SEAT

By SNUG SEAT®, INC Providing Technologies For Mobility, Positioning & Transportation Since 1987

Federal Motor Vehicle Safety Standard #213 is the U.S. standard governing child restraint devices for children weighing less than 50 lbs. The GORILLA was crash tested with a 105 lb. dummy to ensure shell integrity and test forward head excursion. The GORILLA remained fully intact and forward head excursion was less than even the strict Canadian standard for children under 50 lbs. We highly recommend that you obtain crash test results for any child restraint you consider purchasing. Call us toll free at (800) 336-SNUG for a copy of our results.

Circle #69

322

1-800-600-7808, 1-800-755-0601(TTY). The Apple Computer Disability Solutions Store.

*Chris and the entire staff at Aisle 17 have talked to lots of people just like you. They're friendly, they're knowledgeable, they're ready to help.

MAY 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

Recreation

Stefano Cargnel— Becoming A Contender

0102..... 5-DIGIT 22091
A 4006066 EXP 01
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1545

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A SMOOTHER ROAD TO TRAVEL

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING PROGRAM

INFORMATION YOU NEED ... FOR INFORMED DECISIONS

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD" ... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

PROGRAM PERIOD

October 1, 1993 — September 30, 1994

[1] Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges. Up acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.

[2] Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.

A NEW CAR, VAN OR LIGHT TRUCK ... ADAPTIVE EQUIPMENT ... AND ON-THE-SPOT CASH!

Ford and Lincoln-Mercury Divisions

Circle #30

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

MAY 1994
VOL. 24, ISSUE 5

FEATURES

A Father's Gift by Joan K. Blaska 19
David's outings with Dad encourage fun and learning.

Peter's Garden by Roger Bossley 22
Peter and his father plant a garden.

The Arts and Disability by Sally Dorothy Bailey 33
Drama encourages the development of many skills.

The Sky is the Limit by Debbie Meyer 36
A community theatre program includes every member of the family.

Meeting the Challenge by Debra Corwith-Frieden 38
Children with disabilities earn Presidential Sports and Fitness Awards.

Riding the Bus 42
Parents speak out about school transportation.

Racing Wheelchairs for Children by Alynne Landers 52

Recreation Resources 54

DEPARTMENTS

Editor's Desk 2

Letters 4

Search & Respond 8

Familiar Faces 16

Role Models: STEFANO CARGNEL 28
Practice and determination help a young athlete become a contender.

Fathers' Voices: CRYING CAN MAKE YOU A BETTER MAN by Hogan Hilling 47
A father urges other men to "put the macho stuff on hold."

Research: FROM RAGE TO REFORM by Judith A. Mayer 49
A researcher listens to what parents are saying about advocacy.

Directory of Advertisers 58

What's Happening 63

New Products 65

Exceptional Parent Library 66

Children's Page 68

PAGE 54

COVER:
Thirteen-year-old Jason Komenda, of Denver, Colorado reaches for new heights in a rock climbing program sponsored by the National Sports Center for the Disabled. Jason has a visual impairment. (Photo: Jeff Stine)
INSET: *Stefano Cargnel, 16, nationally-ranked competitor in wheelchair track and field events, writes about his experiences in "Role Models," page 28. (Photo: Stacy Tuzik)*

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005.

All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation.

POSTMASTER: Please send address changes to EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

PAGE 33

EDITOR'S DESK

The wonderful stories and pictures in this issue demonstrate how children with disabilities are becoming active in a wide range of exciting recreational and leisure activities. Many of these activities will become lifelong pastimes that will continue to enrich their everyday lives. Not too many years ago, some parents and professionals might have said that it was unrealistic to expect children with disabilities to participate in some of these activities. Often, so much attention was focused on "therapeutic" activities that children and parents did not learn to enjoy recreational pastimes.

STANLEY KLEIN, PH.D.

Gardening, fishing, drama, track and field, fitness! The worlds of children and adults with disabilities are widening because parents like Duane Blaska ("A Father's Gift") and Roger Bossley ("Peter's Garden") share the activities they love with their children. As 16-year-old Stef Cargnel ("Becoming a Contender"), a wheelchair track and field athlete and basketball player, so eloquently explains, sometimes, a parent's encouragement makes all the difference.

Traveling

Now that our difficult winter is finally history, I am traveling and meeting many wonderful readers—both parents and professionals. In April, I flew to Germany to work with early intervention professionals serving Armed Forces families stationed in Europe. I also met with parents and children at the Abilities Expo in New Jersey, at the Frank Porter Graham Child Development Center in Chapel Hill, North Carolina and at the International Parent-to-Parent Conference in Asheville, North Carolina. In May, I will be speaking each day at the Abilities Expo in Anaheim, California and, in August, at the Abilities Expo in Chicago. I look forward to meeting our readers and getting valuable feedback and inspiration at every stop.

Thank you, Ann Landers

Long-time readers know that without the glowing comments about *Exceptional Parent* that have appeared in Ann Landers' widely read columns since 1973, this magazine would not have survived the '70s. On April 19, *Exceptional Parent* was praised once again by America's most widely-read columnist. We always appreciate this recognition—as a result, we know that we will hear from parents from throughout the world who had not previously been aware of the magazine.

Health Care Reform

Several months ago, we urged readers to write to the President and to Congressional representatives regarding concerns about health care reform. Because of the urgency of this issue, we even urged readers to have their children write. We are interested in copies of children's letters as well as any responses they may have received.

Educational Program Award

In past years, each September's educational theme issue has included an award to an exemplary educational program. First, it was called the "Mainstreaming Award," then, the "Inclusion Award." Although we are advocates of inclusion when it includes necessary supportive services for children and teachers, more importantly, we promote good educational choices for parents. For this reason, the award undergoes another name change. This year, it will be called the *Exceptional Parent Annual Educational Program Award.*

We invite nominations for this year's award. Programs will be judged on criteria such as attention to the needs of the whole child—academic, social and recreational; parental participation; teacher support and community participation. Entries should explain, in 500 words or less, how the nominated program meets these criteria. We also encourage you to send pictures. Send nominations to *Exceptional Parent Annual Educational Program Award*, 209 Harvard St., Ste. 303, Brookline, MA 02146. Deadline for entries is July 1, 1994.

EDITOR IN CHIEF
Stanley D. Klein, Ph.D.
Professor of Psychology,
New England College of Optometry

ASSISTANT EDITOR
Kim Schive

EDITORIAL STAFF
Andrew M. Bissaro
Valerie Steele

EDITORIAL INTERNS
Simone Albeck
Zlati Meyer
Annabel Tan

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING
Terri M. Sutera

VICE PRESIDENT, SALES
Kerry J. Cannon

AD TRAFFIC MANAGER
Stefanie Ferrante

CIRCULATION MANAGER
Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS
R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION
Lawrence Qualiano

FINANCE MANAGER
Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc.
Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 58.

BPA International Consumer Magazine Membership Applied for August 1993.

During a 3 year period, children grow an average of 2" in femur length, 1.5" in hip width, and 2.5" in back height.

— extrapolated from *Human Dimensions and Interior Space*

The revolutionary Jay® GS Growth and Positioning System is designed to grow that much and more.

The system includes a new growth Cushion, a new growth Back, and the Jay® Adjustable Solid Seat. Together, these components help position the child's hips and back properly at every step of the growth process. The system is also designed to reduce spasticity and tone.

Call for a free demonstration so that you too can see what a difference a Jay makes!

▲ The Jay GS Growth & Positioning System

JAY® MEDICAL

Jay Medical, Ltd.
P.O. Box 18656
Boulder, Colorado
80308-8656 USA
(303) 442-5529

Toll-free
(800) 648-8282

In Canada, call
(800) 263-3390

© 1992, Jay Medical, Ltd.

Circle #427

LETTERS

The Need for Balance

I'm the parent of a nine-year-old boy who is deaf and has additional disabilities. He was a preemie who was hospitalized for his first five months. I've been an appreciative reader of *Exceptional Parent* since he was a toddler.

I'm writing now because I am troubled by something in the February 1994 issue. You printed a response letter from a parent who wrote with unequivocal enthusiasm about her son's experience with a cochlear implant. It was the only letter published in response to an October 1993 *Search* letter asking for pros and cons on the subject.

I'm sure you are aware of the controversy about cochlear implants. There is much concern that parents will have unrealistic expectations of their post-implanted children, that they will forego the use of sign language in favor of speech therapy and that children will feel enormous pressure to validate their parents' decision to proceed with this new, experimental procedure. Indeed, the procedure has been so recently approved for use in children that it would not surprise me if you did not have a parent willing to write and say, "Don't do it. We did and it was a terrible mistake." At what point would a parent come to that conclusion—three years later? Five?

There hasn't been enough time—although studies citing the incidence of medical complications make one wonder if some parents may be questioning their decision on that basis alone. Some people predict that children who have cochlear implants will be socially isolated. They may not be able to communicate effectively with hearing people nor have the sign language skills to be part of the deaf community. Indeed, some members of the deaf community have likened cochlear implantation to genocide.

It is good to read of a child for whom the implant has worked so well, but hundreds, if not thousands of parents of deaf children will see that letter in *Exceptional Parent* and assume that it will work the same way for their child. Statistics do not support that conclusion, and I'm disappointed that you let the letter run alone.

I know that many of the medical procedures discussed in the magazine have their proponents and detractors, and that you can't always devote space to a full debate. However, I think this is one time you should have stepped in with an editor's qualifying comment, or withheld the letter until you also could have published one that answered C.N.'s request for the downside of cochlear implants. Otherwise, keep up the good work!

B.B.M., Massachusetts

EDITOR'S NOTE: We appreciate your thoughtful letter. Responses to "Search" letters do not always reflect both pros and cons of a controversial issue, but letters published in "Respond" are always representative of those received and forwarded. Responses that come down on one side of an issue often inspire other readers to write letters that disagree with a previously expressed viewpoint—just as you have done. This type of thoughtful, ongoing dialogue informs everyone. Balance happens over time—even if both sides are not presented in the same issue of the magazine.

From the day a child is diagnosed with a disability, parents are exposed to much information and advice on

EXCEPTIONAL PARENT

- *To reach out to parents of children with disabilities and special health care needs.*
- *To empower mothers and fathers by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

LARRY BELFORD, Director, Marketing Research & Strategic Analysis, Ciba-Geigy Pharmaceuticals, Summit, NJ
LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
JEROME SHNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
MARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

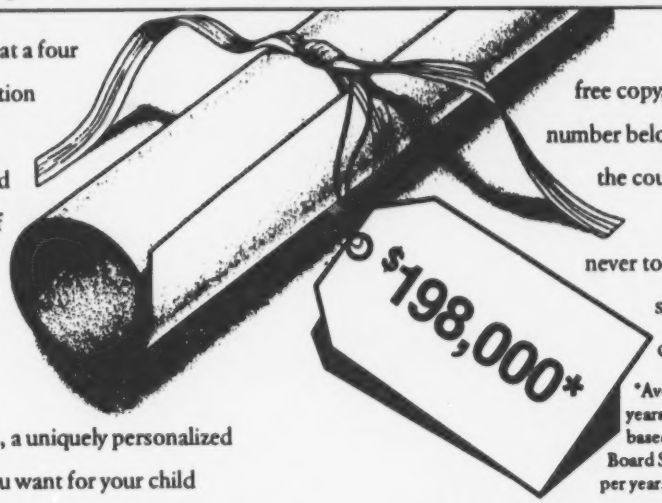
Invest in your child's future now so you can pay for it later.

The CollegeBuilder® Program Free from Merrill Lynch.

$198,000* That's what a four year private college education could cost sixteen years from now. So if your child is likely to be a member of the class of 2006, it's not too early to start saving.

To help you, Merrill Lynch has created the CollegeBuilder® Program, a uniquely personalized analysis based on what you want for your child tomorrow and what you can afford to put away today. Your Merrill Lynch Financial Consultant can help you map out strategies to help meet your family's goals. And, through tax-favored investing, you may be able to minimize the tax bite on your child's college savings.

It's all explained in the CollegeBuilder® Program Brochure.



To receive your free copy, simply call the number below. Or just mail the coupon.

Do it today. It's never too early to start saving for your child's future.

*Average costs for four years of private college are based on the 1989-90 College Board Survey using a 7% increase per year.

1-800-637-7455*, ext.6725

*If you are deaf, you can call 1-800-765-4833, ext. 6725 (TTY). If you are hard-of-hearing, you can call 1-800-765-4HOH, ext. 6725

Mail to: Merrill Lynch Response Center
P.O. Box 30200, New Brunswick, NJ 08989-0200

☐ Please send me a free copy of *CollegeBuilder Program* brochure.

Name _____ Address _____

Business Phone _____ City _____

Home Phone _____ State _____ Zip _____

Merrill Lynch clients, please give name and office address of your Financial Consultant: _____

6725

Merrill Lynch
A tradition of trust.

©1994 Merrill Lynch, Pierce, Fenner & Smith Inc. Member SIPC.

Circle #168

Sometimes a Kid needs to use his hands!

The Mulholland WALKABOUT™ is a dynamic standing system which provides variable spring-activated lift and support. The WALKABOUT allows the child to ambulate "hands free," because sometimes a kid needs to use his hands.

Mulholland Positioning Systems
P.O. Box 391, Santa Paula, CA 93061
(800) 543-4769

Circle # 52

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle # 27

all aspects of childrearing. As the deaf parent of a deaf child, I have developed a great deal of respect for the many hearing parents of deaf children I have met over the years. I have seen these parents become adept at sifting through conflicting recommendations regarding amplification, communication and education to make decisions that are best for their individual children. I do not believe that most parents will assume that what has worked for one child will necessarily work for theirs as well.—K.S.

Magazine is Less Useful

I agree with the letter from C.O. of Washington (February 1994) that your magazine is generally less useful to me than it was even a year ago. I miss the regular feature, *Family Life*, and the additional articles by parents for parents. Advocacy is important—but it's not for everyone. The current emphasis seems to be on telling parents what they should do—the magazine talks *at* us rather than letting parents share *with* each other. Unlike C.O., I wouldn't say that *Exceptional Parent* has become a scholarly journal, but it's become a newsletter for the politically active parents, rather than a forum for all parents.

The first sign of this unresponsiveness to the needs and desires of the parents was when you declared that all parents writing letters would be identified only by initials and state—even if they wanted to give their full names and addresses. This lack of trust in parents' ability to decide whether we want to risk being "known" bothered me, and others. I remember the letters about it at the time, and I don't recall any parent who was glad to be *forced* to be anonymous or to go through your offices for communication. I don't like paternalism; I don't like this we-experts-know-best attitude. And the changes in the magazine since then have all been in the same direction.

The worst of it is that *real* parental empowerment goes by the board when advocacy results in increased control of our children by the bureaucracy. Advocacy organizations want all our children in public schools, so that they'll have the numbers to make an effect. But many of our children will do better in non-public schools that can be much more flexible. We do not yet know enough about how best to educate and rear every child who has a disability—but some bureaucrats are eager to throw a standard IEP at a nonstandard child and then blame the parents if the kid fails. Those of us with strong reservations about the public school system find ourselves at odds not only with the education system, but also with the kind of parent that *Exceptional Parent* now seems to represent.

I wish this magazine would return a little power to the ordinary parent and treat us like grownups. Let us have the option of using our full names and addresses when we write. Print more articles by parents. Let parents do reviews of books they've found helpful rather than just printing excerpts of books you think are important. Encourage diversity in ideas—we do not yet know what will be best for any given child, let alone any group of children. There is no one right way to parent a child with mental retardation, autism or spina bifida. Any one of

your readers might have a unique approach that may help another parent or spark a new line of research. Focusing on government policy is the wrong priority; our children—each individual child—should be the top priority.

I will continue to subscribe, but I wish you hadn't taken the turn you've taken.

E.M., Texas

EDITOR'S NOTE: We appreciate your letter and hope you—and other readers—will continue to be specific in letting us know what you like or dislike about the magazine. We make an effort to be responsive to suggestions.

The policy of using initials of letter-writers rather than full names was announced in 1989. Current editorial staff members agree that it is time to re-evaluate this practice; we would like input from readers on this issue. Currently, we are leaning toward a change in policy that would allow letter-writers to choose between using their full name and state, initials and state or "name withheld upon request."

We are not comfortable with a blanket policy of identifying letter-writers with full addresses. This practice could leave people vulnerable to unwanted solicitations or harassment. Even if these potential problems were not a concern, we would still want to handle the forwarding of initial responses to SEARCH letters, because this process allows us to choose a representative cross-section of letters for publication in RESPOND. It also gives us another avenue of insight into our readers' interests and concerns; the "school bus" response letters published in this issue are a good example. (See page 42.) At the same time, we also are thinking about places where full addresses may be appropriate—if we were to start a pen pal page, for example.

Brain Differences in Autism

I am the president of a parent-run self-help and advocacy group for children's mental health; I have three children with special needs. I was very excited to see Margaret Bauman's article "Brain Differences in Autism" (March 1994). Two of my children—ages four and eighteen—have autism. Finally, someone has said that this disease begins with brain development before birth! I needed to know that there is proof of what we, as parents, have always believed. Thank you!

B.M., Louisiana

Thank You

Thank you for continuing to publish a magazine that provides me with a sense of connection and a feeling of support. I look forward to receiving your magazine each month and often cry while reading it. I cry from profound sorrow when I read of the many other people who are facing such incredible obstacles in their children's lives, and I cry tears of joy when I read of their successes.

And sometimes I cry just because I realize that there are people out there who truly understand what it is like to raise and to love a child the world does not consider "perfect."

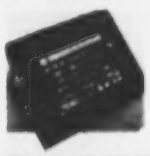
S.G., Hawaii

You Asked DynaVox To Do Even More...

"I want to tell a story."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at 1-800-344-1778.



We Hear You.

TECHNOLOGY INC.

Circle # 68

EASY ACCESS ?
APPLIANCE IN ONLY ONE SHOE ?
SHOP FROM HOME ?

NO PROBLEM!

From Street Hot

3 different pair of footbeds come in each box to custom fit *each shoe* ! Now it's easy to accommodate narrow, medium, and wide width feet, a brace, an appliance, even two different sized feet!

Kids love the cool look ... you'll love the perfect fit!

This is one example of what is inside Starlight's Shop-At-Home Footwear Catalog, which includes the most complete selection of Velcro closure shoes and sneakers you can find in one place. And more. This is a collection with your child in mind.

Write or Phone for FREE Catalog of
Easy Access Styles
STARLIGHT FOOTWEAR COLLECTION
21537 Kapok Circle
Boca Raton, FL 33433
1-800-55-SHOES

Circle # 76

331

SEARCH

Accessible Camps

HEL-P-P-P-P-PPP! I am a single, adoptive mom to nine children, ages 12–25. One of my youngest, Abigail, is a 13-year-old who has cerebral palsy—primarily affecting her lower trunk—and uses a wheelchair. Illiterate when adopted from Korea five years ago, today she is fully mainstreamed in a regular seventh grade class and is a strong student. The problem? She is poorly socialized compared to her peers because of her relative lack of ongoing, informal give and take with friends. She spends most of her time with the family, often in the house. I try to provide socialization opportunities for her, but since I also work full-time, Abby's opportunities to "be a regular seventh grader" are limited.

A residential or "sleep-away" camp would be of enormous help in meeting this very real need. However, I have run up against a brick wall in locating a camp that is fully accessible and both willing to deal with Abby's wheelchair and assume the responsibility of a child who is physically challenged. Abby is fully independent when given enough lead time to meet all of her needs—it's just that most things take her longer, physically, than others. She can use a walker to travel short distances and to make transitions; she gets around on her own but always welcomes a helpful "push" of her chair. She loves the water but does not swim on her own and needs help to get in and out of a pool.

We live just down the road from a camp that is well-known for its programs for children and young adults with disabilities. However, Abby's needs are really not well met there, because her interests and intellectual skills are age-appropriate even though her body does not work well for her. She desperately needs a chance to be with other young teens in a relaxed, fun-filled setting where accommodations can be made for her physical limitations. Any ideas? I simply don't know where to turn!

C.P., New Jersey

EDITOR'S NOTE: Many camps have "counselor-in-training" programs for teenagers. You might want to explore the possibility of your daughter participating in such a program at the camp near your home.

Search and **Respond** is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

G-Tube with Internal Disk

My two-year-old son had a severe hypoxic incident at birth. He has been diagnosed with hypoxic eschemic encephalopathy, cerebral palsy, an uncontrollable seizure disorder and extreme lack of physical growth and development. He also displays a great deal of inconsolable irritability. He arches his back and thrashes to an extent health professionals have not seen in other children.

He had a G-tube insertion recently, but, due to his arching and thrashing movements, the tube pulled out of the stomach and ended up between the stomach and the skin. Resulting complications led to its removal. We can feed him very little orally—this results in dehydration and constipation. Feeding also requires many hours each day. His gastrointestinal specialist has recommended a G-tube with a disk inside the stomach. The disk would prevent unintentional removal of the tube, but its placement is a more complicated procedure and precludes the use of a button.

Some caregivers have related stories of irritation associated with severe arching and the disk, and one doubted that any tube would stay in place with our child. I wonder if an improvement in the ease of his care would be worth an increase in his irritability. We would like to avoid the heartbreak of another hospitalization that could result in a net gain of zero when yet another tube fails to stay in place. On the other hand, the benefits of his G-tube were clear during the short time that it was working. I would be interested in hearing from anyone with a similar experience. We have a third child on the way, so care issues are taking on a new urgency.

R.H., Vermont

Prader-Willi Syndrome with Normal DNA Test

Our three-year-old daughter has been diagnosed with Prader-Willi syndrome. However, no chromosomal deletion or genetic abnormalities show up on DNA probe testing. It is hard to accept this diagnosis when the tests come back negative.

She has severe hypotonia and some of the facial features seen in Prader-Willi. She receives occupational and physical therapy. She has a hard time articulating words; she also bumps into things and falls quite often.

I want to talk to other parents of children with Prader-Willi, especially children with negative DNA tests. I want to know what their lives are like, how the children do in school and what to expect in the future.

C.M., Minnesota

EDITOR'S NOTE: You can contact the Prader-Willi Syndrome Association (PWSA) at 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144, (800) 926-4797. PWSA publishes an informative newsletter for parents.

Rhizotomy

Our three-year-old daughter has spastic quadriplegic cerebral palsy. She is non-ambulatory and does not crawl. Her trunk control is poor, and she can sit unsupported only to a very limited extent—on the floor in a ring-sitting position. Her upper extremities are sig-

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34E1

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34E1

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

Fathers' Voices,
Role Models,
Point of View,
and
Corporations Who Care.

See reverse side for subscription details

nificantly involved as well. She is verbal and of normal intelligence.

Her neurologist has recommended rhizotomy surgery. We've done a lot of research about the procedure, but can't seem to make up our minds. We'd appreciate hearing from parents of children who also have a diagnosis of spastic quadriplegia and who have had rhizotomies. We'd like to hear about any results—good, bad or in-between.

C.S., New York

Chondrodysplaysia Punctata

Our daughter, now almost three years of age, has been diagnosed as having Chondrodysplasia Punctata, also known as Conradi-Hunermann syndrome. This condition is characterized by a broad, flat nose; a short neck; coarse, sparse hair and growth deficiencies. Her doctors told us there was no one else in the United States with this syndrome—imagine our surprise when we came across it in a very old *Search* letter from your magazine. We would like this family or others to get in touch with us. We are very anxious to talk to other families who have dealt with this condition.

B.H. & V.H., New Mexico

Bilateral Aniridia

I am the mother of a bright, beautiful 21-month-old daughter who was born with bilateral aniridia, a rare birth defect involving absence of the iris. Katie's diagnosis also includes foveal and macular hypoplasia, optic nerve hypoplasia, nystagmus, congenital cataracts, hyperopia, strabismus and amblyopia. People with aniridia are considered to be at high risk for glaucoma. Katie's intraocular pressures appear stable and within the normal range.

We have no familial history of aniridia and genetic screening has determined that Katie's chromosomes are normal, so this is thought to be a new genetic mutation or rare autosomal recessive. Katie has no other identified systemic abnormalities and so far, has tested negative for Wilm's tumors. She has some vision which she uses remarkably well. She has not shown any developmental delays.

Because aniridia is so rare, we have had a difficult time researching current articles on the subject and finding ophthalmologists who have a broad base of experience with the condition. I am interested in locating other people with aniridia, or other parents of children with this condition. Perhaps we could form a support group to disseminate information on treatments and knowledgeable specialists. I am particularly interested in contacting people with aniridia who have had cataract surgery or experience with intraocular or contact lenses with a painted, fixed iris.

I am also interested in locating people with aniridia or other abnormalities of the eye in which there was a maternal history of penicillin or penicillin derivatives (i.e. ampicillin, amoxicillin) being used during the first 10 weeks of pregnancy. I know of four or five other non-familial aniridia cases involving mothers who had been given penicillin derivatives before the eighth week of pregnancy—the time when a child's eyes are forming. I wonder if there are more such cases.

S.G., Hawaii

Ritalin and Autism

I am the parent of a four-year-old son with autism. He is also somewhat hyperactive and has a short attention span. He attends a specialized preschool program for three hours every morning. The doctor who diagnosed my son's autism suggested a small dose—2.5–5 mg—of Ritalin on school days only to help control my son's distractibility and improve his concentration.

I cannot find much information or research on Ritalin being used by persons with autism and would appreciate hearing from anyone with experience in this area. I am interested in knowing whether the medication was effective and whether any negative side effects were observed.

L.S., Illinois

Cerebral Arteriovenous Malformation

My seven-year-old son was recently diagnosed with a cerebral arteriovenous malformation (AVM). He has neurological problems including poor fine and gross motor skills and very slow speech. He is in the second grade and makes good grades but has trouble writing because he has an "intention tremor"—a tremor that intensifies when he attempts to perform a coordinated movement. The tremor also makes dressing difficult because he can't work buttons, zippers or snaps. He has trouble opening containers and feeding himself. He drools, chokes on liquids and bites his tongue, lips and cheeks.

After reviewing his MRI and angiogram films, several doctors say that the AVM is too large to treat without significant risk of causing permanent neurological deficits. But one doctor is willing to do embolization therapy—a risky procedure in which he would insert a microcatheter into an artery and inject a substance that causes clotting. The doctor tells us that he cannot cure our son, but hopes to slow the progression of his symptoms.

We feel that embolization may be our son's only hope, but we aren't completely sure it's worth the risk. We have been told that his symptoms will continue to get worse, but no one will say for certain what his prognosis would be without treatment. Is there someone out there who has a child with an AVM who could share their story with us?

P.H., West Virginia

Umbilical Cord Sampling

We are the parents of a two-year-old son who was diagnosed shortly after birth with Neonatal Alloimmune Thrombocytopenia (NAIT). This was the result of PL^{A1-} antibodies. Our son suffered cerebral hemorrhage as a result of a low platelet count at birth. The platelet issue was resolved within 30 days but the hemorrhage was quite large and left our son with a vision impairment and cerebral palsy.

My husband and I want to have another child. Specialists tell us that another pregnancy will involve similar risks but they are confident that they can deliver a healthy baby with careful fetal monitoring and drug therapy. Fetal monitoring will be done by umbilical cord sampling. We are interested in talking to anyone who has had experience with umbilical cord sampling. We are also anxious to speak to parents who have had a child with NAIT, especially parents who have had subsequent pregnancies.

M.L. & T.L., Maryland

RESPOND

Wide Shoes

D.M.G. (September 1993) was looking for a source of wide dress shoes for her 30-year-old daughter who has Down syndrome.

Finding extra-wide shoes in small sizes is practically impossible! My daughter has feet of two different sizes—one is an extra, extra-wide ladies' size five, the other is an extra wide eight-and-a-half. In addition to having a wide foot, my daughter's difficulty in finding shoes that fit is compounded by her leg braces.

I looked *everywhere* before finding a shoe company that carries just the right shoes for our kids—P.W. Minor and Sons, 3 Treadeasy Ave., P.O. Box 678, Batavia, NY 14021-0678, (716) 343-1500. They will custom order mixed-size pairs. They will modify the sole to make it flat instead of wedged. In addition to making wide sizes, they also manufacture many different styles of "extra-depth" shoes that accommodate even the largest braces.

M.S., California

☐ My son also needs wide shoes. I get them from Mason Shoe Manufacturing Company, Chippewa Falls, WI 54774-1905. They carry shoes in widths AA–EEEE and have a catalog with a variety of styles. Their shoes come in women's sizes 4–12 and men's sizes 5–16.

M.B., Missouri

EDITOR'S NOTE: Starlight Footwear (21537 Kapok Circle, Boca Raton, FL 33433, 800/557-4637) is another source of wide shoes in a variety of styles. See their ad on page 7.

Rasmussen Syndrome

S.K.J. (February 1994) is the mother of a nine-year-old who was recently diagnosed with Rasmussen syndrome. In hopes of learning more about her daughter's prognosis, she was looking for other families who have dealt with this condition.

I am the mother of a 14-year-old girl who was diagnosed with Rasmussen syndrome at five years of age. At age seven, she underwent a radical hemispherectomy—the removal of the diseased part of the brain. In Beth's case, the entire left side of her brain was removed. Since leaving the hospital, she has not had one seizure, nor has she taken any medication. Prior to her surgery, she was losing the function of her right hand and had a progressively worsening limp. Her speech and intellectual functioning were deteriorating.

It took two years for Beth to fully recover from the surgery, but now she is a bright, beautiful, happy eighth grader who receives minimal resource help in school. She bowls on a team, swims and is like any "normal" child. Beth would be most willing to talk to you if you would like to see how she is doing.

K.U., Connecticut

Three Kids, Three Disabilities

P.G. (February 1994) is the mother of three very young children with three different disabilities. After genetic testing failed to explain why all her children had disabilities, P.G. hoped some readers might have insight on the question. She also wanted "coping" advice from parents in similar situations.

I also have three children with different problems, though they do not seem to be as involved as your children's. I can't give you any "words of wisdom" about why your children have such different problems; all I can say is that many things happen for which we never know the reason. Let me encourage you by saying that your children are still very young and things generally get easier as they age. Under the *best* of circumstances, it can be very trying to have a three-and-a-half-year-old, a 19-month-old and a newborn.

My eldest child is 12 years old and has had asthma since he was less than a year old. When he was younger, his asthma was frequently out of control. Searching for the right physician and educating myself about the disease made a profound difference for him. If you do not already take your son to an asthma specialist, I would encourage you to do so. It has been my experience that pediatricians are usually not aggressive enough in asthma treatment. A good allergist/asthma specialist really knows how to attack this disease and get results. My son still misses more school and activities than a "normal" child, but things have improved greatly.

My middle child is nine and has a learning disability (LD). As a result of this, he is fairly fragile emotionally—or maybe that has more to do with being the middle child. I also have educated myself about LD, because it is a disability that requires a parent to be assertive in order to get an appropriate school program. It is not too soon for you to begin learning about the special education programs in your school system—as if you already don't have enough to do! Educators use a whole different language when it comes to educating our kids; you must also learn to negotiate the huge bureaucratic maze. Other parents who have already "been there" can be particularly helpful.

My youngest child is five and has ocular albinism, a type of albinism that primarily affects the eyes with only slight skin and hair involvement. She is visually impaired, but not legally blind. We just learned that she, too, has asthma, though we don't believe her condition is as bad as her brother's.

I know what you mean about the constant stress of doctors, therapists and bills. Support from other parents of children with disabilities has been crucial for me. Our local parent-to-parent group's motto—"If your child has special needs, so do you"—is very true. It's incredibly important to remember to take care of yourself so you will be better able to help your little ones. I hope you have someone available to give you a break once in a while. Being a full-time mother or father is exhausting; we all need some time off occasionally.

I hope you will reach out to other parents in your area for support. It seems that parents of children with disabilities are nearly always willing to do whatever they can to help another parent survive this roller coaster ride. The following organizations can provide a wealth of information relevant to your children's disabilities and have great newsletters:

- National Organization for Albinism and Hypopigmentation, 1530 Locust St., #29, Philadelphia, PA 19102-4415;

HALF A LIFT IS *STILL* BETTER THAN WHOLE.

With maximum passenger seat maneuverability, a new easy off/on ground hugging platform, plus reliable all-electric operation.

The Crow River Industries VANGATER™ fold-in-half lift is a timeless classic. When folded it offers half a doorway of usable space for easy loading/unloading, more usable interior space, a clearer side view, and allows the front passenger seat to be almost fully reclined for maximum comfort. But we can't seem to stop trying to improve on perfection.

All-electric reliability.

The enclosed non-hydraulic, all-electric operating mechanism is cleaner and quieter than hydraulic lifts, especially in extreme temperatures. (There's also no leakage or unpleasant odor.) And our new auxiliary electric override provides emergency electrical lift power—not to mention peace of mind—when you need it most.

A flatter platform.

We've made getting on and off the VANGATER™ easier than ever with a new flatter platform that sacrifices nothing in ruggedness and reliability. And you'll find the improved side entry option and exit access great in tight parking situations!

RAPID RESPONSE LINE:
For more information and the name of your closest dealer call *today:*
1-800-488-7688

Circle #14

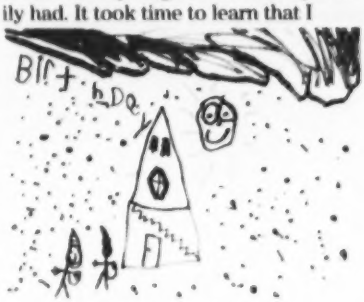
CROW RIVER™
Industries Incorporated
14800 28th Avenue North
Minneapolis, MN 55447 (U.S.A.)
(In Minnesota, 612-559-1680)

- National Association for Parents of the Visually Impaired, P.O. Box 317, Watertown, MA 02272-0317;
- Allergy and Asthma Network/Mothers of Asthmatics, 3554 Chain Bridge Rd., Suite 200, Fairfax, VA 22030-2809.

N.G., Florida

☐ We have much in common—while our children's disabilities are not the same, our lives probably are. I also have had three children with disabilities. My daughter died at age 12 from a rare form of bone-related cancer. That was in 1989, when my two boys were babies. During Emily's two-year illness, both boys were born and eventually diagnosed with disabilities. I remember having two children in the hospital at once and worrying about the third. I remember feeling like an overstretched rubber band and wondering how much longer I could take it all. I felt resentful of parents whose biggest "problem" was that their kid hated having his hair shampooed or that he needed tubes for ear infections. I lost some of my compassion for these people and that really bothered me. I developed defenses against my kids' pain. Sometimes, I felt that if I really started crying, I might never stop, so I tried not to cry. Bad idea!

For a while, I fell into a trap of trying to meet every single need that my family had. It took time to learn that I



"Birthday" by Alex Blum

couldn't do it. I learned to make a list of priorities and to place my husband and me on that list.

I learned to very clearly define my needs and then communicate them. Have you ever met those people who ask if there anything they can do? I began answering those questions with very practical responses, like "Wow, I am so glad you asked that. Do you think you could come over and walk my dog the next time one of my kids is hospitalized?" or "You know, I was just praying that somebody could help my son practice feeding himself once in a while. Would you like to come over next Tuesday morning and see how we're working with him?" When you very specifically outline what you need, all those well-meaning folks either get lost forever or you uncover some very talented people who are on your kids' sides.

I like talking about my kids, so I'll do that for a minute if you don't mind. As I said, Emily died five years ago. Besides having cancer, she also was hearing impaired. She was wonderful, and we were so fortunate to have her. She taught us so much about faith, obedience and love.

Patrick is our seven-year-old. He has the biggest disability of the three kids—Angelman syndrome. He is severely developmentally delayed in all areas and basically non-verbal. He has seizures, a sleeping disorder, fine- and gross-motor deficits and eyes of two different strengths. He has a very affectionate and happy nature and is the love of my life. He is working on feeding and dressing skills and is able to do some pre-school level work on the computer. He walks pretty well, but uses a stroller when we go places. I don't think he is capable of anger.

Jaron, our five-year-old son, was born with eye cancer and lost an eye at one week of age. He is hearing impaired, but has good vision in his remaining eye. Jaron is very entertaining and always is doing something funny. He came up with the idea of starting his own "business" last April; he now earns $5 a month dragging the neighbors' empty trash cans into their backyards on garbage day. We are home-schoolers, so I teach both boys by myself. It is the best decision I ever made, but it is not for everybody.

The other thing I wanted to address is the young ages of your kids. At this point in their lives, your life is *very* intense. Please be encouraged that although it may seem this phase will go on forever, it really does change. Believe it or not, you do get time to catch your breath and even relax eventually. You'll get through it somehow. Really!

B.M., New York

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich ORTHOPAEDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

Circle # 36

338

College With a Personal Attendant

N.T. (February 1993) is the mother of a 15-year-old daughter who is an honors student and wants to attend college. Her daughter has cerebral palsy and uses a motorized wheelchair. She needs extensive assistance for personal care. She has a great deal of difficulty writing, but as a one-finger typist, finds typing equally frustrating. N.T. wanted to hear about the college experiences of people with needs similar to those of her daughter. She also wanted information about colleges with good support services for students with disabilities.

Our daughter is capable of writing, but has required a personal care attendant throughout her college career. Since she first enrolled in college in 1987, we understand that many universities and colleges have taken significant strides toward establishing the necessary programs and offices to meet the needs of their students with disabilities.

Our daughter chose to attend the University of Pennsylvania for her undergraduate work. While Penn did not have an organized program for students with disabilities, the school agreed to provide our daughter with whatever support she required, including building accessibility and assistance in obtaining attendant care. However, some tense moments occurred relating to our ability to find the necessary personal care attendant services. Our daughter requires turning during the night, and we relied on her roommates for this aspect of her care. Penn lived up to its commitments and our daughter enjoyed four happy years there.

Currently, our daughter is a Ph.D. candidate at the University of California Berkeley (UCB). UCB has one of the best programs for students with physical disabilities. It has a dormitory manned 24 hours a day by individuals capable of providing care; it also provides a service that enables its students to find personal care attendants for their respective needs.

M.B. & M.B., Pennsylvania

☐ Prudence K. Tweed and her son, Jason, inspired by their own search for a college that met their educational goals and personal care requirements, compiled *Colleges That Enable: A Guide to Support Services Offered to Physically Disabled Students on 40 U.S. Campuses* (Park Avenue Press, 1989). This book may be helpful.

J.K., New York

EDITOR'S NOTE: The book can be ordered from Colleges that Enable, Inc. (P.O. Box 6585, Wyomissing, PA 19610, 610/376-1551). Suggested, tax-deductible donation is $15.00.

Niki from California—

We received your pen pal letter to J.A., but you did not include a return address for her to write back to you. Please send your address to EXCEPTIONAL PARENT so we can forward it, along with your letter, to J.A.

kid-kart™
cares about kids.

kid-EZ tilt/recline™

made in USA
PATENT PENDING

Proving good looks, convenience and proper positioning work wonderfully together.

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

kid-EZ Adjustable High Chair Base

Circle # 46

FAMILIAR FACES

***Brian Michael Sullivan** of Sarasota, Florida, 16 months old, is described by his mother, Laura, as having "mischief in his eyes." Despite visits to geneticists and other specialists, Brian remains undiagnosed. Laura hopes that all the doctors who wrote about Brian's "dysmorphic features" will see this picture and begin to appreciate this boy with the "million dollar smile."*

*Eight-year-old **Rodrigo** (left) and five-year-old **Jorgé Nevares** live in Guaynabo, Puerto Rico. Jorgé has cerebral palsy. The boys' mother, Carolina, writes that she is looking forward to seeing pictures of other readers' families—"it's a great way for us to share part of our lives with each other."*

*Three-year-old **Brittanne Jade McClain** (right) chats with her friend, Ben, while waiting for the school bus. Brittanne's grandmother, Gloria Reeves, who sent us this picture, wants everyone to know how proud she is of her daughter, Lori—Brittanne's mother. Lori is a full-time college student and according to her mom, a truly "exceptional parent." Lori and Brittanne live in Long Beach, California.*

*This picture of the Mercado brothers of Fort Bragg, North Carolina—14-year-old **John, Jr.** (left) and 11-year-old **Danny**—was taken on Thanksgiving Day, 1993. Danny has multiple disabilities. Danny's mother, Denise, feels that this picture demonstrates the love between the brothers. The family also includes dad, John Sr., and 13-year-old sister Haelan.*

***Heather** and **Kyle Brandon** stop off at the fountain for a drink of water. Heather has CHARGE syndrome; Kyle is her twin brother. The pair, who live in Castro Valley, California, were four years old when this picture was taken.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent?* Send it to: Readers' Photos, *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

COMMUTER

MINIVAN

IN FLOOR RAMP
This patented in-floor ramp system stows the ramp out of sight within the floor and offers these features:

- More wheelchair maneuverability.
- No obstructions inside van doorway.
- Two inch protective side rails (important safety feature recommended by the A.D.A.)
- Complete manual back-up system.
- 3 year/36,000 mile limited warranty.

FOLD-AWAY RAMP
Our Swing-Away ramp system that set the standard for the industry offers the unique features:

- Economically priced.
- 10 years of successful operating history.
- Simple trouble-free operation.
- Complete manual back-up system.
- 3 year/36,000 mile limited warranty.

or fold-down power ramps, extended door and roof, remote controls, and countless other options to suit your needs.

CARE CONCEPTS

3353 W. Osborn, Phoenix, AZ 85017
Call toll free for information and the dealer nearest you:

1-800-288-8267

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

☐ I'm interested in community involvement. Please send more information about Civitan service clubs in my community.

☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name _____

Address _____

City/State/Zip _____

Telephone Number ( ) _____

CIVITAN INTERNATIONAL, P.O. BOX 130220, BIRMINGHAM, AL 35213. **(800) CIVITAN**

FREE SAMPLES. FREE DELIVERY. FREE CATALOG.

Baby, Youth, Adult.

Compare Our Cost & Service On:

Attends	No-Rinse Products
Dignity	Promise
Depends	Tranquility

CompCare has in inventory a full range of sizes. Fast, free delivery anywhere in continental U.S.

1-800-877-7317

CompCare

The Leading Edge of Health Care Excellence

5534 Cortez Road West • Bradenton, FL 34210

CompCare is accredited by Joint Commission on Accreditation of Health Care Organizations.

Circle #14

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle #25

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 5100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

Circle #26

RECREATION

A Father's Gift

David's outings with Dad encourage fun and learning

By Joan K. Blaska

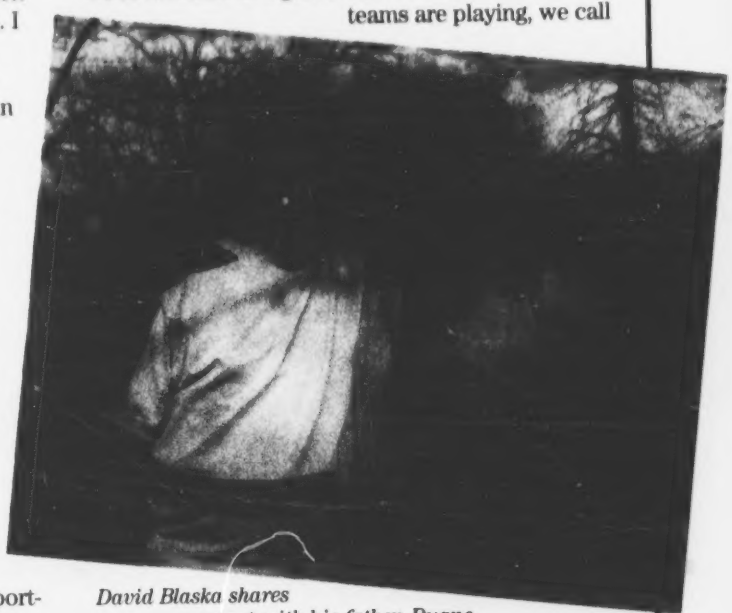
David raced into the house and announced to everyone who would listen, "We caught 19 sunnies and on the way home, I saw three deer!" A couple weeks later, David rushed into the kitchen and shouted, "My team won by one touchdown. I gotta go call Dad—he owes me a quarter!"

These may sound like typical scenes in the lives of children who spend time participating in recreational activities with their parents. But David is our 26-year-old son who has mental retardation and attention deficit hyperactivity disorder. When he was younger and living at home, we privately called him the "white tornado," because he moved so fast. Today, he lives in a group home with three other young men.

Even though David has a developmental delay and some challenging behaviors, his father included him, whenever possible, in his own favorite activities—watching sporting events, fishing and hunting. Over the years, this meant taking David on hundreds of "scouting trips" to find good fishing and hunting spots.

Our family has always enjoyed watching sporting events. David began by watching parts of televised games with his dad; as he gained more control of his behavior, he progressed to attending some of the games. Sometimes, our family would even wager quarters on which team would be the winner. With all this exposure to team sports, one of the first songs David tried to sing was the national anthem! He didn't know the words but tried to sing the melody. He knew that the first strains of the *Star-Spangled Banner* meant that the game was about to begin! Today, he turns up the sound and loudly sings along as best he can.

David's favorite sports are hockey, baseball and football. He attends many games, and has budgeted his money to buy jerseys to wear when his teams play. He also collects trading cards which has helped him learn the names of many players. With help from his high school teachers, David learned to read scores on the Sports page and check the schedule of upcoming games. Today, whenever we're not sure of a game time or don't know which teams are playing, we call David. In return, he often calls to report a score or to let us know who won the quarter—and it's usually him!



David Blaska shares a warm moment with his father, Duane.

Over the years, David's inclusion in recreational activities increased as he gained more control of his behavior. For example, his first hunting outings began as rides in the car, looking at ducks in the ponds and making a game out of naming them. Later, he went along on hunting trips that often involved three generations of our family's men. David was not allowed to carry or use a gun, but he enjoyed roaming alongside Dad as they tried to scare up a grouse or pheasant. On these outings,

David learned the rules of hunting safety and the names of various birds and wild animals.

As a very small boy, David would go out in the boat and fish with his dad. Often, it was just the two of them. David learned to sit still in the boat and enjoy moving across the water. He also learned to bait his hook, cast out his line without messing up the reel, set the line and sometimes, pull in a fish.

On fishing trips, David learned to identify and name many common fish. When he got older, he learned to steer the boat with Dad sitting by his side. The first time I watched David drive the boat, I saw a wonderful look of delight on his face. Tears came to my eyes as I thought of the benefits David had reaped through my husband's patience and willingness to include and teach him.

David proudly displays the "catch of the day."

Over the years, there were times when David and his Dad would return early from an outing that hadn't gone well because of David's challenging behaviors. But this never stopped Dad from trying again.

David's outings with Dad have resulted in many unanticipated benefits. At our house, David feels like he is one of us. While he is aware of his limitations, he feels accepted because we have emphasized what he *can* do. By including him in recreational activities, David's father helped him develop interests that are appropriate for a man; more importantly, these activities have given David lots to talk about!

When David meets someone, he might ask, "Did you see the game—who won?" or "Did you know they traded the catcher?" This small talk is socially appropriate and has helped other people accept David. Sometimes, people don't know what to say to a person with a disability. But all of our family members and friends have lots to talk about with David because of his interests and involvement in these leisure-time activities.

Parents have the opportunity to expose their children to a variety of activities that they may enjoy participating in as adults. Keep in mind that recreational activities are not limited to sports. What do *you* like to do during your free time? Allow your child to choose among your hobbies and participate in the ones that he or she enjoys. For example, David doesn't like to watch golf on television. But sometimes he is happy to walk along in the woods and find lost balls, which he then sells to the rest of us!

Persons with disabilities often lack the skills for leisure activities. As parents, it's important to remember that while our children's disabilities result in varying levels of potential and interest, they all have the capability to participate in some way. We need to ask ourselves, "Am I including my child in activities that I do which are fun and may help prepare my child for the future?"

Through many outings, David's father gave him the priceless gift of time—time to be together, to share and to learn. Because of this gift, David has learned to talk about and enjoy a number of leisure activities. This happened because David's father was willing to share an even greater gift—the gift of love.

Joan K. Blaska, Ph.D., is an associate professor in the Department of Child & Family Studies at St. Cloud State University, St. Cloud, Minnesota. Dr. Blaska trains professionals to work with young children with disabilities and their families. She frequently speaks to parent groups about the joys and challenges of raising children with disabilities.

PI BEAR™ (Physically Inconvenienced)
A Beary Special Friend

PI BEAR is a special friend that children can call their own. PI's three illustrated storybooks, which tell about his accident, recuperation, first day of school and other adventures with friends, can help disabled children understand their own feelings of fear and uncertainty. PI's friends also show others that your friends are friends, no matter what. PI BEAR and his wheelchair are approximately 14" tall. Dressed in a PI BEAR T-shirt, he comes with three story books (in chair backpack), a club membership certificate and a one-year warranty.

For more information, call: 1-800-467BEAR (2327)
Canada inquiries call: 613-258-0177.
VISA/MASTERCARD accepted.
Flexpay Available.
© 1993 PI BEAR CO. Patent pending

Circle # 123

Disability Solutions

Macintosh Bundles

Special Pricing

Support

Convenience

Access

Chris*

1-800-600-7808, 1-800-755-0601(TTY). The Apple Computer Disability Solutions Store.

*Chris and the entire staff at Aisle 17 have talked to lots of people just like you. They're friendly, they're knowledgeable, they're ready to help.

Peter's Garden

My eight-year-old son, Peter, has always spent most of the day with me when I am home. Since much of my free time is spent in the garden, Peter developed a great deal of curiosity about what I was doing. His younger brother, Benjamin, spent time exploring the garden while I worked. However, Peter, who is blind, hesitated to follow, knowing that he would be likely to stumble over the ground and smash some plants.

I initially agreed that the garden should be off-limits and encouraged Peter to "stay out of the way." Then, I reconsidered—since he was so curious, maybe this would be the ideal time to let him learn something about botany and how plants grow. I started thinking about ways to include my son in one of my favorite pastimes.

Planning Peter's Garden

I set aside a 12-square-foot area of the garden for Peter's use and decided on crops that would be easy for him to plant, weed, harvest and even sell. Large or bushy plants with large seeds seemed like a good choice. That first year, we put in Indian corn, miniature pumpkins and gourds.

I knew that the planting and maintenance of his garden plot would be much more clear and meaningful if Peter was involved in the planning process. Peter raised a number of questions during our planning sessions. Many of his questions were very visual. He wondered how big his pumpkins would grow, how much space each plant would need and whether the plants would grow upright or sprawl. We discussed the garden plan in detail—the location of each row, the reasons for choosing these locations and the amount of space between each plant.

Planting

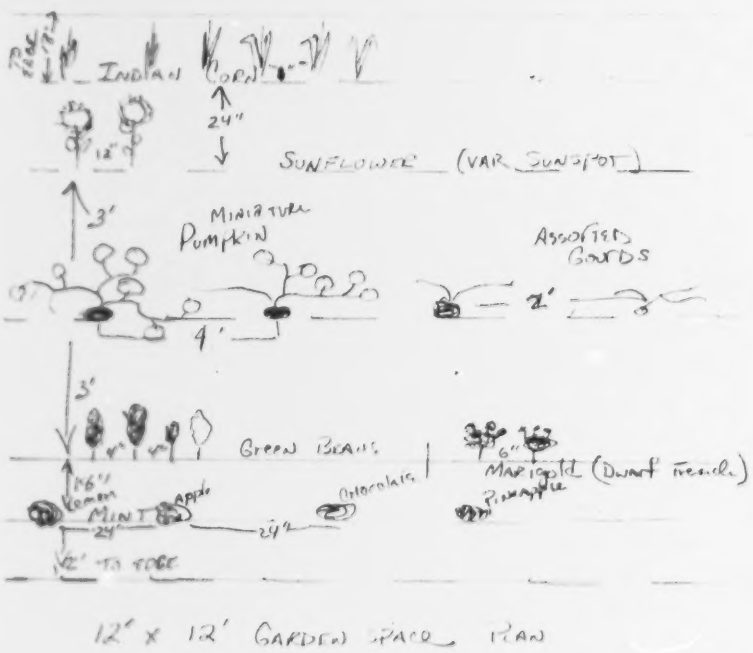
Peter and I worked together to till the garden so it would be smooth enough for him to keep his balance in the area. Then, we strung kite string to mark each row.

Peter planted his pumpkins and gourds in mounds, or hills, directly beneath the string. He counted out six seeds to a hill—later to be thinned out to three plants per mound—and covered them with soil. Then, he used a four-foot section of sapling to measure out the right amount of space between each just-planted hill and the next.

Peter planted corn the same way, by using the string for a guide and a small stick for a measure. He planted kernels of seed corn under the string, about six inches apart.

Garden Maintenance

A clawed garden tool and good mulch—such as leaf mulch or clean straw—will be the only tools a child will need for most small gardens. Simply have the child remove the mulch in one small area



[Near right] This plan for a 12-square-foot space shows a good starter garden for a child with a visual impairment or other disability. [Right] Peter and Benjamin work the garden with a little help from Dad.

BOYS

Gardening is for Everyone!

Adaptations can make gardening more accessible to children and teens with various disabilities.

Some children with visual, motor or intellectual disabilities may have difficulty planting a garden. This task can be made easier by the use of *seed tapes* which eliminate the need to count out seeds and measure the distance between them.

This potting bench is meant to be used from a seated position and meets ADA standards for wheelchair accessibility (Smith & Hawken, Mill Valley, CA)

Raised beds and containers are adaptations that may be useful for wheelchair users and others who can't easily stoop. These containers bring the gardening surface up to the level of a standard table. Raised beds and containers come in various sizes and materials and are available for indoor or outdoor use. A helpful, free publication—*Gardening in Raised Beds and Containers for the Elderly and Physically Handicapped*—is available from the People-Plant Council, Office of Consumer Horticulture, Virginia Tech University, Blacksburg, VA 24061-0327.

Equipment

Many types of gardening equipment have been adapted; other, commercially-available products also have useful features.

Specialty handle tools solve a number of problems. *Extended handle lengths* make gardening easier for children who have difficulties bending or kneeling, or who work a ground-level garden from a wheelchair. Individuals with limited manual dexterity and grip may use these tools by strapping the handle to their forearm. *Normal or extra-short handle lengths* are beneficial for gardeners working a raised-bed garden from a wheelchair. *Enlarged-grip handles* assist individuals with limited manual dexterity and grip strength. *Lightweight-handle tools* may be easier to carry and use than traditional metal-handle tools. And *rubber-grip handles* are often easier for any child to grasp.

Gardening stools and knee pads are designed to alleviate pain or discomfort associated with bending, stooping, kneeling and getting up from the ground. Additionally, some stools have built-up frames which can help a child get into and out of a kneeling position.

Many commercially-available products also have helpful features—hose nozzles now come with a "lock-on" feature; ride-on lawnmowers have hand controls; many pruning and trimming tools are now motorized and made of lighter-weight materials. Check local hardware or garden stores.

Handle padding can always be added to help the youngest gardeners grasp tools. Sets of commercially-made, plastic toy tools may be appropriate for the small hands of beginning horticulturists. However, a set of "real" tools for children is offered by Smith & Hawken, 25 Corte Medera Ave, Mill Valley, CA 94941, (415) 383-2000.

Resources

- The *American Horticultural Therapy Association* (AHTA) promotes the use of horticulture as a therapeutic, rehabilitative activity. It operates a national employment project for persons with disabilities, sponsors continuing education programs and publishes reports and periodicals. **American Horticultural Therapy Association**, 362A Christopher Ave., Gaithersburg, MD 20879, (301) 948-3010.
- *ABLEDATA*, an assistive technology and adaptive communications database, can provide a list of adapted garden tool manufacturers and products. **ABLEDATA**, 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TDD).

at a time, and rough up the ground a little to keep it from becoming too compacted by rain. Be sure to cover all the areas with mulch again.

After our garden had been put in, I tilled the ground between the rows a few times. Soon, both plants and weeds were sprouting. When the plants were large enough, I showed Peter what pumpkin and gourd plants felt like at the stem—fuzzy and somewhat prickly. Now he could easily differentiate them from the weeds. We waited until the corn plants were fairly thick at the base; then, Peter also was able to distinguish them from the weeds he pulled out from around their thick stalks.

Gardening turned out to be an activity we could enjoy together—from initial planning stages to end product.

Crops for Kids

Not every variety of plant is a good choice for a child with a visual impairment or other disability, but there are plenty of good ones from which to choose. Besides the plants I chose for Peter's first garden, other good crops include the bush varieties of string beans, potatoes, peppers, tomatoes, beets and various herbs and flowers.

Bushy string beans have uniformly large beans that ripen at the same time. These are easy for a child to harvest and less prone to insect infestation—and who wants to touch bugs while picking beans?

Pepper plants are not too difficult for children to plant and will live even if they are not planted in the most delicate fashion. Tomatoes, too, if planted deeply enough, will survive a child's sometimes

348

imperfect handling. Both peppers and tomatoes can be staked to allow children with visual and muscular impairments to locate the plants, weed around them and pick their fruits. Again, mulching these plants will reduce the need for weeding.

Seed potatoes are another good crop for children. Potatoes can be planted at ground level and covered in heavy soil or planted three inches deep in loam. If the plants are mulched with leaves, they will need little weeding. Peter and I planted seed potatoes in his second garden; in the fall, we dug them up. I taught him to follow the

Peter (right) and brother Benjamin plant seed potatoes.

stem with his hands to search for spuds. Most spuds will be found on the roots very close to the stem.

Beets are another root crop to raise and weed—they are hardy biennials that are a good choice for longer-term gardens. They can be mulched after the plants are three inches tall.

Children enjoy growing mint plants. Mints have square stems which make them easy to distinguish from weeds. They do best when lightly mulched and planted in moist places. Mints come in many different varieties with smells from chocolate to apple to lemon—an exciting crop for a child with a visual impairment. Older children may wish to grow other herbs such as dill or fennel; enterprising youngsters can even find a market for them.

Easily-grown flowers include marigolds and sunflowers. Marigolds grow quickly and are extremely hardy. For a child with a visual impairment, they have an odor that makes them easily distinguishable from weeds. If mulched, sunflowers of the Sunspot variety grow quickly to a height of two feet and produce large 10-inch flowers. Their seeds will attract goldfinches in the late summer.

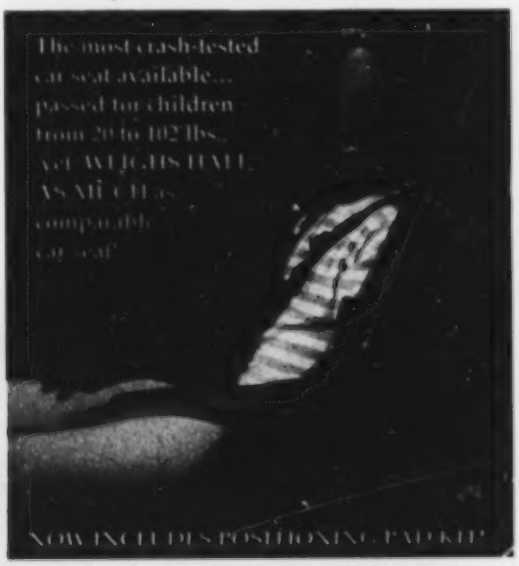
Marketing

Many garden products can be easily marketed. Gourds, miniature pumpkins and miniature Indian corn find ready buyers at flea markets, garage sales or craft fairs in late August through October. All of my children, including Peter, have had experience selling these and other crops.

*Super **Light**, Super **Strong**, Super **Safe**, Super **Simple**...the Columbia Car Seat has been the #1 choice since 1986* Thousands of Columbia Car Seats are now in use, and we have received some amazing crash stories. One grateful father in Louisiana sent a picture of his badly crumpled van and said, "My 4-year-old son escaped without a scratch, did not even break his glasses." One mother in Colorado wrote, "Thank you for making such a wonderful car seat! I really like how comfortable [my son] is in it. On Dec. 5, 1991, we were hit extremely hard on the passenger side. My 6-year-old son, a healthy 65 pounds, was not hurt at all because your car seat held him so securely."

Our years of *real world* experience give you peace of mind knowing your child is comfortable and secure in our seat!

PLUS it's lightweight, easy to use, good-looking and easy to care for!



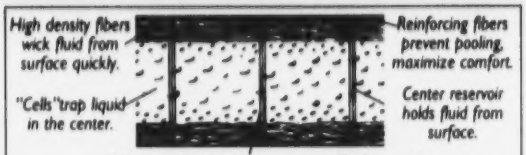
Ask for our FREE Full Color Catalog of convenient, helpful products

The Columbia Car Seat is your best value!

- The LIGHTEST special car seat–easy to handle!
- Fits easily into ALL vehicles, no matter how compact!
- EXCEEDS all Federal safety standards!
- Approved for car, school bus and even airplane travel!
- Fits your choice of 4 stroller bases!

MEDICAL MFG. CORP. (800) 454-6612
Dept CL P.O.Box 653
Pacific Palisades, CA 90272

The Next Step In Dealing With Incontinence.


High density fibers wick fluid from surface quickly.
"Cells" trap liquid in the center.
Reinforcing fibers prevent pooling, maximize comfort.
Center reservoir holds fluid from surface.
Fibers bundled in coils to transmit fluid to center and spread it throughout the garment.

The chart above shows how Hypersorb™ works. The photo shows how good it looks doing it. A new level of efficiency, a new level of fashion.

Reusable and guaranteed for one year (details available), in girls, women, boys and mens models, it's what's next. For orders or a catalog, just call.

Girl's Model

TMI
TECHNOMARKETING INC
307 Bacon Road • Rougemont North Carolina 27572
(919) 477-1387 • Fax (919) 477-2294
©1994, TMI. Hypersorb Patent Pending.

Circle # 122

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

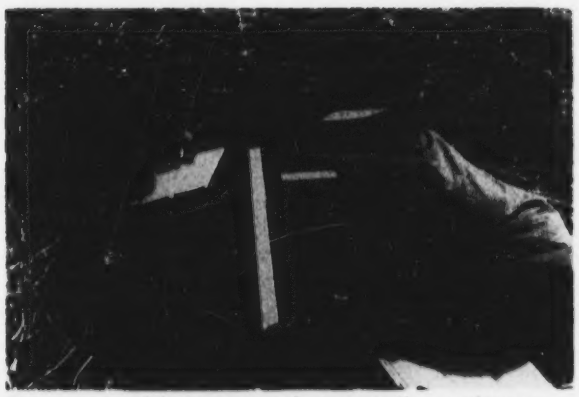
"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Rueben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 66



Peter uses a stick to measure the correct distance between seedings.

Indian corn should be sold with the husks on—peeled back and dried one week prior to sale. Pumpkins should be picked when the stem is starting to dry and the surface is not easily scratched by a fingernail. Gourds are easier to sell when they are dried—this means waiting until the next season—and scrubbed to a natural color or painted. The American Gourd Society (Box 274, Mount Gilead, OH 43338, 419/362-6446) has free information packets on various types of gourds; they also sell gourd seeds.

Benefits of Gardening

I am glad I rethought my initial reluctance to include Peter in gardening activities. His gardening experiences have led to an increased enjoyment of the outdoors and greater knowledge of plants and plant growth. More than that, however, gardening turned out to be an activity we could enjoy together—from initial planning stages to end product.

Roger Bossley is a retired agriculture teacher, freelance writer and speaker who lives in Northeastern Ohio. He and his wife, Susan, have six children, including three adopted children with special needs. The family recently returned from living in the Ukraine for five months where they helped Crimean Tatars reestablish agriculture-based villages after the fall of communism.

CHARLES C THOMAS • PUBLISHER

- ☐ Camerer, M. C. Gore—**A PARENT'S GUIDE TO COPING WITH ADOLESCENT FRIENDSHIPS: The Three Musketeer Phenomenon.** '94, 186 pp. (7 × 10), 1 il.
- ☐ Love, Harold D. & Freddie W. Litton—**TEACHING READING TO DISABLED AND HANDICAPPED LEARNERS.** '94, 280 pp. (7 × 10), 8 il., 23 tables.
- ☐ Giordano, Gerald—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.
- ☐ Brigance, Albert H. & Charles H. Hargis—**EDUCATIONAL ASSESSMENT: Insuring That All Students Succeed in School.** '93, 182 pp. (7 × 10), 4 il., $38.75.
- ☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $36.75.
- ☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.
- ☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 × 10), $47.75.
- ☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¼ × 9¼), 113 il., 19 tables, $59.75.
- ☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.
- ☐ Chandler, Louis A. & Virginia J. Johnson-**USING PROJECTIVE TECHNIQUES WITH CHILDREN: A Guide to Clinical Assessment.** '91, 140 pp. (7 × 10), 13 il., 1 table, $30.75.
- ☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, $52.75.
- ☐ Harley, Randall K., Mila B. Truan & LaRhea D. Sanford—**COMMUNICATION SKILLS FOR VISUALLY IMPAIRED LEARNERS.** '88, 356 pp. (6¼ × 9¼), 41 il., $53.00.
- ☐ Blanco, Ralph F. & David F. Bogacki—**PRESCRIPTIONS FOR CHILDREN WITH LEARNING AND ADJUSTMENT PROBLEMS: A Consultant's Desk Reference. (3rd Ed.)** '88, 264 pp. (7 × 10), $33.00.
- ☐ Dudley, James R.—**LIVING WITH STIGMA: The Plight of the People Who We Label Mentally Retarded.** '83, 146 pp., 4 tables, $22.00.
- ☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 276 pp., 13 il., 1 table.
- ☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 314 pp. (6¼ × 9¼), 100 il., 14 tables.
- ☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.
- ☐ Kass, Corrine E. & Cleborne D. Maddux—**A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice.** '93, 222 pp. (7 × 10), 3 il., $45.75.
- ☐ Vaughan, C. Edwin—**THE STRUGGLE OF BLIND PEOPLE FOR SELF-DETERMINATION: The Dependency-Rehabilitation Conflict; Empowerment in the Blindness Community.** '93, 256 pp. (7 × 10), 3 il., $41.00.
- ☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 x 10), 21 il., $37.75.
- ☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $50.50.
- ☐ Lombana, Judy H.—**GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed.** '92, 198 pp. (7 × 10), 1 table, $45.75.
- ☐ Trief, Ellen—**WORKING WITH VISUALLY IMPAIRED YOUNG STUDENTS: A Curriculum Guide for Birth–3 Year Olds.** '92, 230 pp. (7 × 10), 3 il., $41.75.
- ☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.
- ☐ Hughes, Barry K.—**PARENTING A CHILD WITH TRAUMATIC BRAIN INJURY.** '90, 111 pp. (7 × 10), 3 il., $28.50.
- ☐ Durán, Elva—**TEACHING THE MODERATELY AND SEVERELY HANDICAPPED STUDENT AND AUTISTIC ADOLESCENT: With Particular Attention to Bilingual Special Education.** '88, 250 pp. (7 × 10), 5 il., 3 tables, $45.50.
- ☐ Maloff, Chalda & Susan Macduff Wood—**BUSINESS AND SOCIAL ETIQUETTE WITH DISABLED PEOPLE: A Guide to Getting Along With Persons Who Have Impairments of Mobility, Vision, Hearing, or Speech.** '88, 162 pp. (7 × 10), $37.00.
- ☐ Tuttle, Dean W.—**SELF-ESTEEM AND ADJUSTING WITH BLINDNESS: The Process of Responding to Life's Demands.** '84, 336 pp., 13 il., $44.00.

Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice

2600 South First Street Springfield • Illinois • 62794-9265

Stefano Cargnel— Becoming A Contender

All you need are practice and determination.

Stefano Cargnel is a 16-year-old high school sophomore who lives in Carlstadt, New Jersey. Stef, who has spina bifida, is a wheelchair athlete who is nationally ranked in track and field. He is also an avid basketball player. We asked him to write an article for EXCEPTIONAL PARENT *about his involvement in athletics.*

I am very active in sports—wheelchair sports, that is. But I wasn't always so athletic; I used to hang around the house after school with nothing to do. At the time, I didn't feel I had any choice. "What can a handicapped kid do with his time other than school, television and homework?" I would ask myself. I had always wanted to play sports, but where? With whom? It was obvious that I couldn't participate in "normal" sports like football or Little League. The more I thought about what I was missing, the worse I felt and the madder I got.

Of course, peer pressure didn't exactly help. My classmates constantly reminded me of what I could not do; this only added to my problems. It seemed that I was always getting into trouble for fighting. If someone challenged me, I accepted. Fighting was a way to blow off steam. It really began to get out of hand, however, and I spent a lot of time in the principal's office. I wasn't a bad kid; I just couldn't handle the frustration anymore. Everyone was concerned—my teachers, my principal and especially my parents—but no one knew what to do.

My mother's answer changed my life...

Then, one winter day in 1989, my mother came home from a spina bifida meeting with a big smile on her face. I asked why she was smiling, not realizing that her answer would change my life forever.

She said that a man named Andy Chasanoff, who coached a wheelchair track and field team at the Children's Specialized Hospital in Mountainside, New Jersey, had come to the meeting to give a presentation about the program. The word "wheelchair" made me cringe; I had never used a wheelchair in my life! Still, I thought, "why not?"—at the rate I was going, it was worth a try.

I will never forget the first practice I attended. I was scared to death and didn't have a clue about what to say or do. When people asked me questions, I just nodded or gave a one-word answer. Andy introduced himself and tried to explain the program. I just sat there like a dead weight and listened.

Then, Andy asked me if I wanted to try out a wheelchair he had. After pondering for a minute, I agreed. He went into a room, unlocked a storage closet and rolled out an odd-looking black and yellow wheelchair. I didn't know what to do—sit in it or run! I must admit that it took some coaching, but finally, I sat down. It felt strange and uncomfortable; I sat there totally still and silent. Everyone looked at me as if waiting for a response, and I began to hesitantly push the wheels back and forth in place.

"Hey, this isn't so bad!"

Slowly, everything seemed to become less scary. By that point, I had made up my mind to come back, even though I didn't know what would lie ahead.

Junior Nationals

My first year was extremely difficult. Being new to sports, I had no idea of what to expect, so I just took things as they came. I wasn't very good, and I knew it. No matter what I did, I got blown off the track. In field, I placed well—only because there was very little competition in my age division.

I heard all the other athletes buzzing about something called the Junior National Championships. I knew only that this was the meet where the best of the best showed their stuff. The coach told me that the Nationals are held in a different state every year and participants must qualify to compete. The qualifying concept intrigued me. It brought out a desire to improve, and I started to work harder.

In my first season on the team, I qualified for the Nationals. I was in a daze. For the first time in a long time, I was proud of what I had accomplished.

I knew I would not win at my first Nationals, but I didn't care—I just wanted to do my best. I met new people, made friends and learned more and more every day. For the first time in my life, I felt accepted for who I was.

Stefano (right) races against the clock at the 1991 Children's Specialized Hospital Invitational Wheelchair Meet in Rozelle Park, New Jersey; and tosses the shot put (above) in the 1993 competition.

In my second season, I qualified for Nationals again. By now I was developing a comfort zone for competition and the pressures it brought. I was becoming a true athlete.

Becoming a Contender

By my third year, I was beginning to develop physically. Finally, I could make a muscle and actually see a bulge appear on my arm. At fourteen, I had grown into a leadership role because I had become the oldest person on my team. Now, I was competing on a higher level. I had gone from a puny kid to a well-built athlete who could compete seriously. I wasn't what is considered "elite," but I was holding my own. I was beginning to get noticed by other athletes and coaches—not just as an athlete, but also as a person. For the first time, I felt popular. It was great! My confidence soared. I don't think it was cockiness; for once, I just believed in myself.

I knew that the National Championships that year would be a whole new ball game. I could barely sleep the night before we left for Orlando, Florida. I arrived at the airport feeling like a million dollars. Everyone was buzzing with excitement. The plane touched down an hour or so later, and the minute I saw the palm trees, I smiled—I knew that this year would be different and special.

The first few days in Orlando were devoted to relaxation and pleasure. We visited Disney World, M.G.M. Studios and Epcot Center. But once competition began, I was all business. I had made a mental game plan to handle each race and throwing event.

With my newfound seriousness, I fared better than ever before. I finished seventh in javelin and placed in the top ten in shot-put and discus. Although I did not qualify for track finals, I placed within the top ten in all my divisional races. I had finally broken through. I was a contender.

Rehab Technology One Stop Shopping

- ❑ Augmentative Communication
- ❑ Customized Mobility Equipment
- ❑ Seating and Positioning
- ❑ Funding Reports and Justifications
- ❑ Adapted Toys
- ❑ Orthotics

Children's Specialized, the state's only pediatric rehabilitation hospital, provides inpatient and outpatient treatment for children and adolescents, newborns to 21 years old.

Speak with the Specialists at Children's Specialized.

CHILDREN'S SPECIALIZED HOSPITAL

CSH-OCEAN
94 Stevens Road
Toms River, NJ 08755
(908) 914-1100

150 New Providence Road
Mountainside, NJ 07092
(908) 233-3720

CSH-Outpatient Center
330 South Avenue
Fanwood, NJ 07023
(908) 233-3720

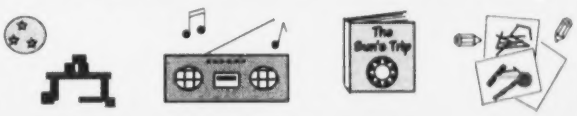
Circle # 185

It Takes Two To Talk

A Parent's Guide To Helping Children Communicate

by Ayala Manolson M.Sc. CCC

Help your child learn to talk during everyday routines and activities!



GAMES ◆ MUSIC ◆ BOOKS ◆ ART

A beautifully illustrated, user-friendly guidebook for parents of children with language delays. Written by a speech-language pathologist, it contains practical information on how to facilitate communication and language learning within everyday conversations, routines and activities. Used by speech-language pathologists, parents and educators around the world! 151 pages. 1992 edition. $32 (includes shipping and handling).

The Hanen Program®

To order, or for a free catalogue, call:
1-800-828-1376 ~ Imaginart, Dept EPM,
307 Arizona St, Bisbee, AZ 85603

Circle # 187

The Turning Point

When Stefano was eight or nine years old, he went through a very difficult period. He had a lot of energy and nowhere to vent it. He dreamed of playing football and basketball, but he was very limited in what he could do using his leg braces. His father and I had focused on his learning to walk and being mainstreamed into public schools. Stefano was very frustrated and angry.

Wheelchair sports was the turning point in our lives. Once Stef got started, there was no stopping him. Racing provided him with freedom and speed, taught him about being part of a team and returned the motivation he had lost.

Over the next few years, Stef became self-confident, gained a healthy sense of competition and was given the opportunity to travel to national competitions. He also became involved with a group of adults who played wheelchair basketball for Kessler Institute—there are no junior teams in New Jersey. While he's had some great role models in both sports, I have to give him a lot of credit for his perseverance with basketball. He continued to practice every week—as the "baby" among much older, experienced men—literally, getting "creamed" at times. It definitely was a school of hard knocks.

Three-year-old Stefano (center) served as March of Dimes Poster Child for Bergen/Passaic Counties, New Jersey.

Stef has won many medals and awards, but none made me prouder than the huge trophy he won in 1992. It was the Tri-State area "Coaches' Award" given to the competitor who had demonstrated the most improvement, growth and development in racing and team spirit during the previous year.

Wheelchair sports has been the best thing to happen in Stef's life. I hope that his story will encourage you and your children, maybe even recruit some wheelchair athletes of the future. No, not every kid who uses a chair will be able to become—or even want to become—an athlete, but there is something out there for him or her to excel in and be proud of, something that will build self esteem and character.

Stef is now the oldest member of the "Lightning Wheels" track and field team. His young teammates look up to him for guidance and friendship. He truly has become a role model for them, as well as many others.

—Lisa Cargnel

354

Discussing strategy: *Stefano confers with coach Andy Chasanoff at a recent practice.*

It has been two years and two more Nationals since Orlando. I am now highly ranked nationally in both track and field.

Wheelchair Basketball

The same year I began track and field, I started playing wheelchair basketball. I asked my grammar school advisor if there were any teams in the area; she said she would look into it. About a week later, she told me about a recreational team that was funded by the Kessler Institute. I figured I would give it a try.

The following Monday, I went to my first practice. Boy, was it tough! I was this little kid who could barely reach the rim from the foul line, and here I was playing with a bunch of men who, it seemed, could hit shots from anywhere! It was a real learning experience.

Now, five years later, I blend right in with those guys I used to think were the wheelchair equivalents of Michael Jordan. Looking back, I think the challenge of playing with adults as a kid made me a better player.

Practice and Determination

Beyond the physical advantages sports have given me, they also have equipped me with a better outlook on life and given me confidence to achieve whatever I strive for. Before sports, I could barely hold a football, never mind throw it, and I would never have had the nerve to ask a girl out on a date. Now, these things are just basic parts of my new life.

Getting involved in sports, on any level, can be an essential stepping stone in life. My involvement in sports has changed me for the better. I feel that everyone—both able-bodied and disabled—should make sports a part of their lives. All you need are practice and determination. These two qualities alone can make or break an athlete. With this in mind, I suggest that all those interested in wheelchair sports give it a try.

5 Models Available Now

BIGFOOT

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Bigfoot 4 X 4 Inc. St. Louis, MO

Circle #42

STROLL INTO A NEW WORLD

Not only can you take your child to places you both would like to go, our **SPECIAL NEEDS STROLLER PACK** will give your child a whole new outlook.

STROLLER Pack

A Way of Life

1 800 487 9652

SKAGGS & INGALLS INC

Circle # 78

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

Circle #18

The Arts and Disability

by Sally Dorothy Bailey

The arts can greatly enhance every aspect of our lives: learning, work, play, relationships and identity formation. In fact, because they are so basic and so life-affirming, the arts often open up new avenues for stimulation, communication and growth. If this is true for people who don't have disabilities, it is equally so for people who do have them.

This article is an excerpt from WINGS TO FLY: BRINGING THEATRE ARTS TO STUDENTS WITH SPECIAL NEEDS (Woodbine House, 1993), a comprehensive nuts-and-bolts handbook for people who are interested in bringing the benefits of drama to students with a variety of disabilities. WINGS TO FLY is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.

Disabilities—whether physical, cognitive or emotional—cause a great deal of frustration in the lives of those who have them... The arts break through barriers and limitations. They offer participants many possibilities and options for successful expression of feelings and ideas. Difficulty on one level of perception or communication does not negate enjoyment or participation on another... For example, someone who has difficulty expressing herself in words because of a speech disorder or learning disability may be able to express herself through pantomime or dance. A student who can't write about something that happened to her might be able to act it out or sing about it...

If an individual can experience success, be valued for her ideas and have her feelings validated, her self-confidence and self-esteem begin to grow. When attitudes about the self change, obstacles become surmountable...

Making friends and sharing experiences creates a sense of belonging to the community, of having the right to exist and enjoy life alongside everyone else. To be acknowledged for artistic creations leads to the desire to contribute more—to the self, family, friends and community...

Specific Skills Which Drama Develops

Each art form helps student artists develop specific skills. A look at some of the skills that drama enhances will show how participation in theater arts might benefit a person who has a disability.

Listening: Directions to games must be listened to in order to play. Stories must be heard before they can be acted out. While acting out a scene, each actor must listen to the other actors in order to know when to say her line and what to say...

Eye Contact: Many children who have cognitive disabilities or low self-esteem have difficulty making eye contact with others. Eye contact is part of listening and receiving information from others. It is also part of sharing information with others about what you are thinking and feeling. Being able to make eye contact with another person enhances trust as well as communication.

There are many drama games that stress eye contact and therefore

Performers, as well as audiences, enjoy musical theatre productions.

PHOTO: ALLISON WALKER

develop the ability to use it on stage and in real life…

Awareness of the Body in Space: Some people need a lot of "personal space" and some need just a little. If someone breaks the boundaries of your personal space without your permission, you probably will feel threatened. Sometimes students are aware of their own personal space, but not of the fact that others have it as well.

Awareness of personal space is a cultural concept that is taught non-verbally. Children normally learn it through observing their parents as they interact within the family and in the world at large. Children who have special needs sometimes miss out on a lot of information that is taught non-verbally because their attention is occupied with other emotional, physical or information-processing concerns. This lack of awareness of body and personal space boundaries can lead to personal misunderstandings and fights…

Shape-shifting or transformation exercises stress changing your physical self into other animals or objects, both large and small, and moving in different ways. Slow motion/fast motion exercises can create the awareness of how your body moves through space and at which speeds you have more or less control.

Once a student understands how her body inhabits the space around her, she can begin to learn how her body interacts with other bodies in space. Many movement games teach spatial relationships. Others teach how to touch appropriately and in a non-aggressive manner.

BATH-MATE ™

Water Powered Bath Lift

The Bath-Mate fits your existing tub without modifications

Water pressure alone supplies the lifting action. Lifts up to 350lbs.

The bath chair pivots outward for safe transfers.

Safe Bathing Promotes more Independence....

The Bath-Mate raises slowly to wheelchair height and lowers within 2 inches of tub bottom.

Optional:
- Seat Belts
- Arm Rest

(800)947-6565

P.O. Box 80095 Ontario, Ca. 91758

Circle #67

Physical Expressiveness: Guessing games and transformation games require students to use their bodies in different ways to communicate an idea to others. Pantomime necessitates that students imitate an action as clearly as possible. Creating a character different from oneself encourages expressing emotions in different ways and exploring how other people move and express themselves.

Facial Expressiveness: For humans, the face carries more emotional information than any other part. In fact, communication begins with the face… Working with facial expressiveness in drama class develops ease and appropriateness of expression as well as the ability to interpret the meaning of facial expressions in others.

Verbal Expressiveness: The most obvious way drama can enhance verbal expressiveness is by training students to speak clearly and understandably. Through improvisation, students can learn to translate thoughts and emotions into words… Expressing how a character in a fictional context feels can provide a student with enough emotional distance to be able to sort through her own feelings and choose appropriate words…

Focus and Concentration: Focus and concentration are crucial for an actor to develop in order to create an exciting performance on stage… Focusing on drama games and activities, which are of short duration, but which create intense, enjoyable feelings, a student begins to learn how to focus her attention. The immediate positive feedback from her body, her emotions, the teacher and her fellow students reinforces focused behavior and encourages her to pay attention to what is going on in the classroom.

Flexibility and Problem Solving Skills: Many children with special needs, in trying to cope with physical, relational or educational situations that seem to be out of their control, can become very tight and rigid in the choices they are willing to make. They stop taking risks and limit themselves to a narrow range of behavior that may or may not be appropriate to the current moment.

For example, a child who has difficulty controlling her body movements because of cerebral palsy could develop an inflexible need to always be in control of every interpersonal interaction. Things have to go her way or no way at all. If she can't call the shots, she might whine, complain, protest, have a temper tantrum or refuse to participate. Obviously, these are not productive coping strategies. No one can always control other people's behavior or choices…

In drama class, students have the opportunity to try out different roles and behaviors in a safe situation. Different strategies for solving a problem can be acted

358

out and the pros and cons of each evaluated and discussed. Changing points of view on a situation through role reversal often helps students open up their personal perspective on a specific problem or on their general orientation toward themselves and others. Just the experience of standing in another's shoes for a little while teaches flexibility and opens up the possibility that other choices do exist and might be considered.

Social Interaction: Sometimes children who have special needs have poor group interaction skills because they don't have enough opportunities to practice them...

A wide variety of group experiences are available for students in a drama classroom. The entire class might act out something together in a parallel fashion, expressing different versions of the same idea side by side without interacting. The teacher might lead the group in a transformation game where everyone changes from elephants to monkeys to thorn bushes. The whole group might play an interactive game... Individuals can take turns getting up in front of the group and pantomiming different activities or singing a song. Partners can work together on games and exercises. Small groups can invent an improvisational scene or play a game in which they have to work together to solve a problem. In each type of group experience, students have the opportunity to make positive contact with other students, to give and take ideas, to resolve conflicts and to make friends.

Self-Esteem: Because they are different from other children in their neighborhood or school and because they may not succeed in academic and social settings—the two main arenas of childhood—children with disabilities may not feel good about themselves.

Drama is a self-esteem builder. Through dramatic experiences in class and in performances, children can share the creative, vulnerable, and absolutely unique aspects of themselves with others. They can explore who they are, experience success, and begin to feel proud of themselves.

Sally Dorothy Bailey, R.D.T., is an established playwright, director and drama therapist with an M.F.A. degree from Trinity University. She is director of the Special Needs Program at the Bethesda Academy of Performing Arts in Bethesda, Maryland—a program she established in 1988. Her work at BAPA includes teaching special needs classes and directing three barrier-free performing companies for individuals with and without disabilities.

LIFE
CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL®
THREE-OR-FOUR WHEEL, RWD SCOOTER
Choose the ride that's fit for you. Regal is available in seven models, all ergonomically designed to give your journeys freedom of choice and comfort.

BACK-SAVER™
REAR EXTERIOR WHEELCHAIR LIFT
Easy to use. No lifting. Fully automatic. Raises and stores manual wheelchairs with the turn of a key activated switch. Only 1 of 14 different Bruno Lifts.

CURB-SIDER™
SCOOTER & WHEELCHAIR LIFT
Unique 180-degree power rotation lets you pick up next to or behind your vehicle. Ideal for use in vans and trucks with liftgate or tailgate rear openings.

ELECTRA-RIDE™
STAIRWAY ELEVATOR SYSTEM
Low-cost, battery-powered stairway elevator. Needs no special wiring. Operates even if there is a power outage. To give your journeys peace of mind.

BRUNO®
INDEPENDENT LIVING AIDS

© BRUNO INDEPENDENT LIVING AIDS, INC. 1993

CALL 1-800-882-8183 TOLL FREE OR 1-414-567-4990 FAX 1-414-567-4341
BRUNO INDEPENDENT LIVING AIDS, INC. 1780 EXECUTIVE DRIVE PO BOX 84 OCONOMOWOC WISCONSIN 53066

Circle #8

The Sky is the Limit

by Debbie Meyer

It all started six years ago with an ad in the paper—"Wanted: Drama Teacher." My educational theatre program was at a standstill at the time, and I was looking for something to do. The position, however, turned out to be a bit more than I had anticipated. The Baltimore County Department of Recreation was looking for someone to teach a theatre program for 12 young adults with developmental disabilities.

Could I do it? Well, I had a degree in theatre arts, and I also had a degree in psychology. This might be a way to combine both interests. Sure, why not?

As I began thinking about the task, I became more excited about the challenge. I needed to create a way for anyone, regardless of their ability or disability, to participate in and develop a love of theatre. Since musical theatre was my first love, I wanted to find a way to share this experience with my students.

Creating a musical theatre program for individuals with multiple disabilities would not be simple. Some people were non-verbal and I wondered how to include them. Then, I came up with the idea of having actors and actresses sing along with recorded voices. This allowed everyone to participate.

Choreography development was another challenge—some people were not too steady on their feet; others used wheelchairs. The choreography had to be exciting enough to maintain audience interest, but simple enough to avoid frustration on the part of the performers.

As we continued to rehearse, previously hidden talents were uncovered. We all worked hard to create costumes and scenery. I learned to be flexible. Every director begins a project with a certain vision, but knows that the show develops according to the talents of the cast.

William Lundy and Anita Jacksits perform in a "Sky is the Limit" production. William began his involvement with theatre as a student in the first musical theatre program. He is now active in integrated community theatre productions.

Finally, it was "opening night." We performed our show for friends and family. It was a huge extravaganza, and no one was left untouched by the experience.

Such a marvelous experience was bound to grow. With the support of Baltimore County Department of Recreation and Parks, the program expanded and won numerous honors and awards. One day, my boss asked if I was interested in starting an integrated theatre program for people with and without disabilities. Once more I said, "Sure, why not!"

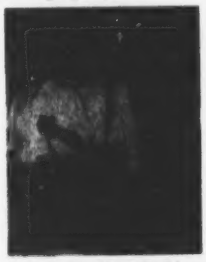
That was the beginning of "The Sky is the Limit" Community Theatre. Housed in a 700-seat auditorium, "The Sky is the Limit" now performs two large-production, family musicals every year. It also sponsors five 20-week musical theatre programs, a tap program, a six-week integrated summer performing arts camp for children and performing arts classes for children. People with disabilities are encouraged to participate in all programs and performances.

For some, community theatre has become a "family affair." Cathy Steffen had always loved the theatre, but when her third child, Ryan, was diagnosed with developmental disabilities and autism, she thought her perform-

From left, Tom Sawyer (Brookes Evans), Becky Thatcher (Sarah Collier) and Huck Finn (Tommy Lewis) do some exploring in this scene from the community theatre production of "Tom Sawyer." In addition to her community theatre involvement, Sarah, who has Charcot-Marie-Tooth disease, is beginning her second year as a "goodwill ambassador" for Maryland's Muscular Dystrophy Association.

360

ing days were over. When Cathy saw an announcement about "The Sky is the Limit" in her local paper, she knew it was the answer to her prayers. Not only does she perform in all of our shows, but so do her children, Sarah, Jenny and, of course, Ryan—he played Little Jack Horner in our production of *Babes in Toyland* last year.



Ryan Steffen (left), William Lundy and Lisa Dillon performing in the community theatre production of "Tom Sawyer."

Of course, none of our programs would be successful without the commitment of our wonderful staff and volunteers. Parental involvement has also been crucial. These programs would not exist without the courage and support of many people.

Anyone with a love of the arts can start a program like ours. We keep growing and growing—your program can too. Give it a try. After all, the sky is the limit!

Debbie Meyer is Director of Therapeutic Creative Arts for the Baltimore County Department of Recreation and Parks. She lives in Baltimore, Maryland with her husband, Frank, and their four-year-old son, Hank.

Don't take our word for it. Ask Mom ....

"Justin enjoys being able to see everything around him. His headrest has helped with his schoolwork since he doesn't constantly struggle to keep his head up!" **Sandy Keethler, Justin's mom**

WHITMYER BIOMECHANIX, INC.

848 Blountstown Hwy. Suite H
Tallahassee, Florida 32304
(904) 575-5510
FAX (904) 576-4798

Circle # 188

Laureate

TALKING SOFTWARE FOR SPECIAL NEEDS

Free Book!

Laureate's book, *Sequential Software for Language Intervention*, describes seven stages of language development from birth to adulthood. Learn how our talking software can improve your child's communication skills.

Call for a FREE BOOK and our new 1994 catalog.
1-800-562-6801

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Circle # 48

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

Meeting the Challenge

by Debra Corwith-Frieden

The President's Council on Physical Fitness and Sports (PCPFS) was established by President Dwight Eisenhower in 1956. It was one of the first steps in a national campaign to help American youth "shape up." In 1958, I was one of the program's first eager participants. I remember pushing myself to perform the required number of sit-ups and chin-ups in hopes of earning the coveted Presidential Physical Fitness Award. My sister, Marcia, who has developmental disabilities, was not given an opportunity to participate in this—or any—fitness program.

Much has changed since 1958. Today, PCPFS sports and physical fitness programs are open to people of all ages, including individuals with special needs.

Presidential Sports Awards

The *Presidential Sports Award* program was developed by PCPFS in 1972 and is administered by the Amateur Athletic Union (AAU/Presidential Sports Awards, P.O. Box 68207, Indianapolis, IN 46268-0207). The program's purpose is to encourage physical activity and exercise for people of all ages—anyone over the age of six may earn an award. Awards are available for almost every imaginable sport or fitness activity.

PHOTOGRAPH BY ROBIN CHRISTMAN

After riding a stationary bike for the first time, eight-year-old Ali Provitt shares a happy moment with his teacher, Michelle Cristo.

Participants in the program keep track of their activity on a "fitness log." Fitness logs and qualifying standards for each sport can be obtained from the AAU. Adaptations to qualifying standards may be made for individual disabilities. When qualifying standards have been met, send the log and $6.00 per award back to AAU. An award packet consists of a certificate of achievement from President Clinton, letter of congratulations from the chairman of PCPFS, embroidered emblem or blazer patch, sports bag identification tag and shoe pocket which can be used to hold identification, money, keys or other small items.

Family members who participate in the program and earn awards together receive a special *Family Fitness Award.* Christine Spain, Director of Research, Planning and Special Projects at PCPFS, says that earning a Family Fitness Award can be a fun activity for parents to share with their children. It can promote family togetherness while introducing children to fitness activities.

The President's Challenge

Under the guidance of physical educators and youth leaders, young people ages 6 to 17 can earn one of three *Youth Physical Fitness Awards.* To earn an award, students must participate in five tests: 1) Curl-ups: a measure of abdominal strength and endurance; 2) Shuttle Run: a measure of speed and coordination; 3) One-Mile Run/Walk: a measure of heart/lung endurance; 4) Pull-ups: a measure of upper body strength and endurance and 5) V-Sit Reach: a measure of flexibility. A child's level of performance on these five tests determines the award he or she will receive—the Presidential Physical Fitness Award, the National Fitness Award or the Participant Physical Fitness Award.

PHOTOGRAPH BY ROBIN CHRISTMAN

Students practice the V-sit.

Students with physical disabilities can earn Presidential Youth Fitness Awards through the use of modified award criteria. PCPFS allows modifications to or substitutions for any of the five tests in order to accommodate an individual child's disability. The instructor may use his or her discretion in deciding whether the child has qualified at a Presidential, National or Participant award level.

Program Benefits

In 1991, after eight years of teaching swimming to students with mental retardation, I became a classroom teacher of students with multiple handicaps. My experience with the *Presidential Fitness Mile Lap Swim for Special Populations* (see sidebar) had shown me that fitness award programs could pay off in many ways. Along with

This **WIZARD®** Will Amaze You!

Comfortable and fully adjustable, the WIZARD offers tilt-in-space, a fully reclining back, and elevating legrests....A magic act that no other pediatric wheelchair can perform, and it's standard with every unit!

The WIZARD easily separates into two components weighing less than 20 lbs. each....Mom can effortlessly load the WIZARD into the trunk!

The WIZARD offers these advantages

- Made of strong steel tubing, the durable WIZARD frame is guaranteed for the Lifetime of the User.
- Grows with your child from age 1 to 10 without having to purchase an expensive growth kit.
- Tackles any terrain with it's heavy duty 8"x2" front caster tires.

The Wizard
PEDIATRIC WHEELCHAIR
BY SNUG SEAT®

1-800-336-7684
Fax 1-704-847-9577
In Canada 1-800-667-3422

By SNUG SEAT®, INC. Providing Technologies For Mobility, Positioning & Transportation Since 1987

Circle #69

When you have a child with multiple disabilities, life suddenly becomes very complicated. You may be referred from one specialist to another...only to receive conflicting reports. No one seems to have the answers.

At Heartspring, the answer to multiple questions can be obtained from specialists who work together to diagnose each child's needs and recommend education programs or treatments to meet those needs. So parents don't waste precious weeks or months trying to discover where to turn.

For 60 years Heartspring has been a lifeline of hope for parents and their children with special needs.

During a comprehensive assessment, the team of professionals at Heartspring work to analyze your child's needs. These professionals, who devote the necessary time and attention to each child, include speech/language therapists, occupational and physical therapists, a developmental pediatrician, a psychologist, a special education teacher, and a case manager. Parents are also a critical part of their child's team.

This method of assessment has worked well for children with autism, mental retardation, behavior disorders, cerebral palsy, seizure disorders, hearing and/or vision impairments, and developmental delays. All assessments are conducted in a caring residential school atmosphere by professionals who have chosen to work with children with multiple disabilities.

If you – or someone you know – needs a lifeline for hope in the assessment and treatment of a child with special needs, call today.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800-835-1043

Formerly the Institute of Logopedics

1934 - Celebrating 60 Years Of Service - 1994

Circle # 38

The Presidential Fitness Mile Lap Swim for Special Populations

The *Presidential Fitness Mile Lap Swim for Special Populations* is a unique component of the AAU/Presidential Sports Awards. This program allows children 10 or older who have multiple disabilities to earn a *Presidential Sports Award* by swimming a minimum of one mile (5,280 feet) within 90 hours during a four-month period. Children and teens with no prior swimming experience have successfully earned this award.

Interested people can implement this program in their communities by scheduling training times at a community pool facility, obtaining local sponsorship and recruiting volunteer coaches. Local newspapers can help spread the word.

An informative brochure has more information on the program and suggestions for implementing the program in local communities. Contact Debra Corwith-Frieden, 3539 Ada Vista, Uniontown, OH 44685, (216) 699-8956.

improved physical condition, I had seen my swimming students develop motivation, self-confidence and pride in their accomplishments. I promised myself that I would give each of my students the opportunity to earn a Presidential Youth Fitness Award. Our school's physical and occupational therapists worked with me and another teacher to modify each fitness test for individual students. Then, we recruited a classroom of fourth grade students to help our students train.

We established various training stations in the school gym and trained four times a week. Integrated groups of six children rotated from one exercise station to the next. The fourth-graders demonstrated each exercise and gave hands-on assistance as needed.

This program reaped a number of benefits. Special needs students gained the expected physical benefits of a program of regular exercise; they also gained new social acceptance. Within months, a new spirit of unity and openness came about as the integration that began in the gym spread throughout the school. Regular-education students spent lunch and recess times with students who had disabilities. In the hallways, students with disabilities were greeted by name, verbally or through sign language. Classroom exchanges took place.

Fond Memories

For one fourth-grader and her brother, the program had special meaning. Ruth's mother wrote, "My son, Andy, had many severe disabilities. Even though he never spoke a word in his fifteen years of life, he conveyed volumes in body language. It was so heartwarming to watch his reactions to the fourth graders helping with this program.

"Andy's sister, Ruth, was the only fourth-grader to be able to claim a sibling with special needs. Though dealing with disabilities was not new to her, she learned that her brother's challenges were not the same as the others in the class—each person had his or her own special package of abilities. It was wonderful to have her come home each day and share the triumphs of her brother and his classmates. I will never forget the day of the awards ceremony when Ruth pushed Andy's wheelchair up to the front of the room so that he could receive his award. It was a picture that will never be erased from my mind, because it was one of the last things they did together. Andy passed away several weeks later. All of his fourth grade friends still think of him fondly as an honorary member of the class of 2000."

For more information...

For further information on any PCPFS program, contact: The President's Council on Physical Fitness and Sports, 701 Pennsylvania Ave., NW, Suite 250, Washington, DC 20004, (202) 272-3427.

Debra Corwith-Frieden lives in Uniontown, Ohio, with her husband and two children. Currently, she is a supervisor at the HELP Foundation, an agency that provides supported living services to adults with disabili-

THE IMPERIUM 100 SYSTEM INCLUDES THE BASIC UNIT, AN APPLIANCE MODULE, A LAMP MODULE AND A BATTERY CHARGER.

Empower your child.

THE IMPERIUM 100 ENVIRONMENTAL CONTROL SYSTEM PUTS INDEPENDENCE WITHIN YOUR CHILD'S REACH

THE IMPERIUM 100 IS AN ENVIRONMENTAL CONTROL UNIT DESIGNED ESPECIALLY FOR PEOPLE WITH LIMITED MOBILITY. SIMPLE TO OPERATE, THE IMPERIUM 100 ENABLES CHILDREN TO TURN ELECTRICAL APPLIANCES ON AND OFF WITH THE TOUCH OF A SINGLE SWITCH. AND WITH THE ABILITY TO TURN LIGHTS AND RADIOS ON AND OFF, CHILDREN DO MORE THAN CONTROL THEIR OWN ENVIRONMENT – THEY REACH A HIGHER LEVEL OF INDEPENDENCE. IT'S SO SIMPLE YOUR CHILD WILL BE USING IT IN MINUTES.

➤ AS EASY TO USE AS IT IS TO AFFORD. PRICED TO MEET THE FINANCIAL NEEDS OF PARENTS, THE IMPERIUM 100 IS THE MOST AFFORDABLE ENVIRONMENTAL CONTROL UNIT OF ITS KIND. ITS MODULAR DESIGN AND AFFORDABLE ADD-ON COMPONENTS ALLOW FOR EASY SYSTEM EXPANSION TO MEET YOUR HOUSEHOLD'S UNIQUE NEEDS. ➤ CALL US AT 1-800-944-8002 FOR A FREE VIDEO AND BROCHURE EXPLAINING HOW THE IMPERIUM 100 SYSTEM WILL HELP YOUR CHILD BECOME MORE INDEPENDENT!

IMPERIUM™
THE POWER TO COMMAND

TELEDYNE BROWN ENGINEERING • 300 SPARKMAN DR. N.W. • HUNTSVILLE, AL 35807 • 1-800-944-8002

Circle # 120

Riding the Bus

It's hard to predict the reaction a given SEARCH letter will bring, but we were astounded by the deluge of mail—and the outpouring of opinion and emotion—elicited by a question about the pros and cons of riding the school bus (February 1994). Clearly, this issue hit a nerve with many readers. Some of them share their thoughts here.

Our son is seven years old and mildly autistic. During the four years he has been in school, either his dad, the baby-sitter or I have driven him to school. Our family has found this to be a very satisfactory arrangement. Almost every one of our son's teachers, however, has urged us to have our son ride the school bus instead. They say they believe very strongly that riding the school bus is an important part of going to school. Is there any research that supports the idea that riding the school bus is better than having a family member drive the child in a car? Are the teachers likely to prefer the bus for reasons they are not discussing?

N.S., New York

Joy Dillman:

Your letter really pushed a button with me. I have experience in just about every angle of this issue and am delighted that you have voiced this question. While I know of no studies on this topic, I can speak from my own observations and experiences.

I am the mother of an 18-year-old son. Dave had infantile spasms and developmental delays beginning at eight months. He attended a parent-infant program starting at 15 months and various special education programs through second grade and was totally mainstreamed thereafter. Dave had some autistic characteristics as a preschooler and continues to have some social difficulties. We have transported him ourselves, used school buses and utilized car pools during all his school years.

Joy Dillman and son Dave celebrate his 17th birthday.

I also am a professional. Currently, I am the educational specialist and center director of an early childhood intervention program. Our program provides limited transportation services, primarily to children whose parents have no means of coming in for services.

As a parent, I much preferred to transport my son. It seems that the most meaningful communication I have had with any of my children occurred while in the car. These were, and still are, precious times—the phone doesn't ring, chores aren't calling and the enticements of TV and Nintendo aren't present.

When Dave was small, the car provided a major context for learning language. He learned the letters of the alphabet—"M" for McDonald's, "K" for K-Mart—and began to read by observing billboards and street signs. He learned about colors, sizes and the concept of same and different. He learned action verbs and adjectives as we talked about the things we saw along the way. As he got older, we played math games by making up stories about topics he liked. When we didn't feel like talking, we listened to tapes of classic children's stories, rhymes and songs. Because he had a very short attention span and tended to be anxious and obsessed about certain thoughts, he needed a lot of structure. We used our time in the car to go over the day's schedule and review the rules he needed to remember before school. Immediately after school, he was ready to talk about what went on during the day. During the ride home, he talked more than at any other time of the day.

When my son was in preschool, I usually accompanied him to his classroom each morning. This gave me contact with his teacher and other parents. I felt good that I knew what was going on at school. I also made some great friends—both his teachers and other parents. I didn't realize how important this was until he began riding the bus, and I missed it so much. But because I had gone back to work, riding the bus, at least part of the time, became a necessity.

I was never pressured to utilize bus transportation, but I have worked with other professionals who did pressure families. They felt that riding the bus was an important part of learning to separate from parents and

366

to become independent and responsible. They believed that riding the bus aided social development. Some teachers may prefer that children ride the bus because it gives them an additional measure of control over their time with the child. They may not wish to be distracted by parents coming and going and prefer that the children arrive together rather than individually. Part of their agenda may be to break down the overprotection that they feel the parents have for their child.

While transportation is a needed service and a godsend to some families, no one should be pressured to use it. To some children, the bus ride can be very disorganizing and overstimulating. Transportation decisions should be based on the best interests of the child and the family.

Joy Dillman lives in Round Rock, Texas with her husband, Ken, and their children, Dave and Mary. Dave is a senior at Brentwood Christian High School and plans to attend Abilene Christian University in the fall. Joy is director of the PRIDE (Parents' Resources for Infant Development Enrichment) Program in West Williamson County, Texas. Her career is a direct result of being a parent participant in early intervention programs.

Debbie Johnson:

I have a six-year-old son with autism, and I take him to school each day. At times, his teachers have stressed the "need" for Joshua to ride the bus, but they never gave any solid reasons as to its benefits.

Joshua Johnson, age six.

I have found that the time we spend together each morning and afternoon is some of our best quality time. We share a prayer together before we leave in the morning, and, as we travel, I constantly feed him verbal information. I talk about everything from the things we see outside to our plans for the night or weekend. Joshua learns a lot during this time. I also have the benefit of daily teacher-parent contact. I get firsthand information about his progress and am able to give my input regarding his educational program.

I also get to know the other students and see how my son is relating to them. Just last week, I had the privilege of seeing my son and another boy hug each other—on their own, without any prompting. If Joshua rode the bus, I never would have seen that. It means a lot to parents like us to know that our children have friends.

My advice to you is this: if your child wants to ride the bus, let him ride it—but on his time frame, not the teacher's. Pushing a child too fast can do more harm than good and if your way of doing things is working for you and your child, why change just because the professionals tell you to? You have more credentials than they have; you are the parent.

Debbie Johnson lives in Suffolk, Virginia with her husband and son. She works part-time as a real estate title searcher.

Norene Parker

My 20-year-old son, Mike, has multiple disabilities. I have been driving a special education school bus for the last 10 years. I first began driving Mike's bus when it became increasingly difficult to make adequate day care arrangements for him. I discovered that I loved driving the bus, so I have continued. During the course of my day, I transport children as young as 18 months and as old as 21 years.

Yes, your seven-year-old probably should be riding the bus just as his classmates do. As crazy as it may sound, it is an integral part of the school day. It's a chance for the kids to socialize and make friends outside their immediate classrooms. It fosters independence and self-reliance. Students use this time to grumble about teachers and homework and to exchange ideas on topics not usually discussed in school—video games, the opposite sex, sports and

Mike Parker, Jr., dressed up for his first prom, poses for a photo in front of Mom's bus.

367

TRIAID
REHABILITATION PRODUCTS

Picture Of Fun!

The best Europe has to offer at American prices. Three different styles in various sizes for all ages. Call or send for our new color catalog.

VISA-MasterCard Now Available
CALL TOLL FREE 1-800-306-6777
P.O. Box 1364 Cumberland, Maryland 21502 • 301-759-3525
Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle #82

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

other subjects. Your son would feel like he was more a part of the school program if he arrived and departed just as the other students do. This may be a boost to his self-esteem. Being made to feel different may be more distressing than he realizes and may hurt the feelings of some of his classmates. Usually, being picked up by a parent is a special treat.

Yes, the teachers may prefer that your son ride the bus for other reasons that they are not discussing. Do you always arrive on time? Are you anxious to chat with them while they are trying to get other students to their buses? Do you keep them talking after the buses have left, preventing them from getting home to their own families? Do you expect a detailed report of your son's day each afternoon? There could be many reasons that the teachers would prefer not to see a parent twice a day, but most likely, they simply know that your child will mature faster if he takes some small steps toward independence. Don't worry—in 10 years of transporting several hundred students, I have yet to find one that didn't absolutely love riding the bus!

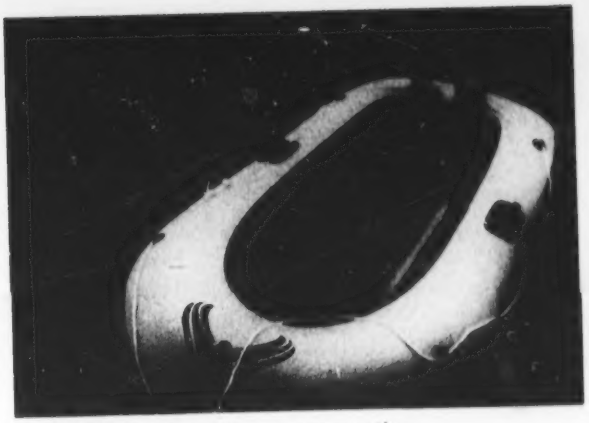
Norene Parker lives in Ellicott City, Maryland, with her husband, Mike, and two sons—Mike, Jr. and Billy. For the past ten years, Norene and her husband have led a Boy Scout troop for boys with disabilities—Mike, Jr. earned the rank of Eagle Scout in 1992. Norene drives Howard County Bus Number 77.

Lynn Cahill:
Our son is also seven years old and mildly autistic. He began school four years ago. Placing David into a special program that would benefit him didn't bother me—we all want the best for our children. However, I worried about putting my young son on a bus. I was very apprehensive, but my husband encouraged me to give it a try.

David's first day of school arrived. The bus stopped in front of our house and its doors opened. I waited for the tantrum and tears to begin. To my surprise, David got on the bus, took a seat and never looked back. For me, the decision to let David ride the bus was one of the most difficult ones I ever had to make. But for David, the bus signaled the beginning of a new adventure, and he enjoyed every minute of it.

Riding the bus has helped David gain a sense of independence and self-esteem. He gets very excited when he sees the bus because this is part of his very structured day—and he desperately needs structure. He even looks for the bus to come on weekends. His bus rides also make him feel like part of his school community because it is something that he shares with his peers.

We don't know the preference of David's teachers, but we do know that driving our son to school would not work for us. He would expect us to stay, and he



David Cahill enjoys his summer vacation.

would balk at getting out of the car. An upheaval like this in the morning would affect his actions for the rest of the day.

Whatever your decision is, however, it should be honored and respected by all involved. We strongly feel that parents know what is best for their child.

Lynn Cahill lives in Chicago, Illinois, with her husband, Paul, and three sons. She does volunteer work for her local PTA and Cub Scouts.

Kathy Andrus:
When our three-year-old daughter, Kate, who was blind and had a congenital heart problem, began preschool in our public school system, we were strongly urged to put her on a school bus. Since the school was only a mile and a half from our house, we really didn't see the need for her to ride a bus. She often rode to school on the back of my bicycle, or I transported her back and forth in the car. Since Kate was the youngest of our five daughters, we found this time in the car or on the bike to be a special time to share together.

Throughout my daughter's preschool years, teachers and administrators continued to nag me to put her on the bus. One administrator actually told me that I was depriving her of a valuable educational experience! Neither my husband nor I ever had to ride a school bus until we accompanied our children on school field trips. We found it to be pretty low on the scale of "valuable educational experiences!" Preschool children were strapped into their seats—one child per seat—and "quiet" was enforced. We never gave into the pressure to put Kate on the bus during her preschool years, but we often felt bullied and intimidated by professionals who felt that we were not doing the right thing for our child.

When Kate began elementary school on the other side of our vast county, she began riding the bus. For the first two years, her ride was about an hour long each way with only two other children on the bus. The

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA

Circle #12

- Improves coordination, postural control and muscle tone.
- Provides independence.
- Secured in center with belt or seat.
- Trade-in policy.
- S.M.L
- Covered by most insurance companies.

THE WATER WALKER

- Prone or supine support.
- Contour lines that allow use of arms and legs.
- Straps to secure person on float.
- Pillow for head support.
- S.M.L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

VISA MasterCard

Circle #170

PROTECTION PANTS

Swimsuit Diapers

Prevents Embarrassing Pool Accidents
Soft, lightweight, outer layer with wick-away inner lining. Tapered design provides protection under a regular swimsuit.

INFANTS ($9.95)
S, M,L, XL, SL
YOUTH ($14.95)
4/5, 6/7, 8/9, 10/11, 12/13,14/15
ADULT ($17.95)
S, M, L, XL

Dry Night Pants

Keeps Outer Clothing or Bedding Dry
Reusable, comfortable pants offer wetness protection. Waterproof knit outer layer with super absorbent inner pad. Holds one cup liquid.

YOUTH ($18.95)
2/3, 4/5, 6/7, 8/9, 10/11, 12/13, 14/15
ADULT ($21.95)
S, M, L, XL

Shipping $3.95
Visa/MC Accepted
Ask for free catalog

Family Clubhouse
6 Chiles Ave.
Asheville, NC 28803
1-800-876-1574

Circle #174

third year, a child who lived in another direction was added, and Kate's bus ride began to last up to two hours, morning and afternoon. The bus had poor air circulation and no air conditioning. She began getting migraine headaches and vomiting.

I located a draft copy of an EPA study showing that diesel fumes may have adverse effects on individuals, like my daughter, who are more susceptible to respiratory tract problems. We eventually got her off of the bus and convinced the county to provide a taxi service for her—but not before we had to go through quite a bit of frustration dealing with the system and listening to all of the benefits of riding the bus! I finally invited the superintendent of schools and any other interested professionals to ride the bus for one day so that they, too, could share this wonderful experience. There were no takers.

Ten-year-old Kate Andrus (front) with older sisters (clockwise from top left) Molly, Margaret, Robin and Beth.

I have never figured out why many educators of children with special needs insist that riding the bus is so valuable. I think it may be one way that they can avoid contact with the parents on a daily basis. These children are just children who happen to learn a little differently. I have never heard teachers of non-special needs children urge bus transportation. For all families, the bus should be an option for convenience, and families should not be made to feel guilty for declining that option.

A year and a half ago, our daughter died of complications from her heart condition. I do not regret one moment that I spent driving her to school. The last months after her heart surgery and before she died, Kate returned to school for part of each day. I drove her the long distance to school, waited for her until she tired each day, then drove her home. These were some of our most cherished times together. Enjoy the moments that you share with your son whether it is in the car or anywhere else!

Kathy Andrus lives in Alexandria, Virginia, with her husband, Nick, and four daughters. She has an M.S. in Child Development and does volunteer work with various family support groups in Fairfax County, Virginia.

Crying Can Make You a Better Man

by Hogan Hilling

Many men have a difficult time expressing their feelings—especially when it comes to crying. Like most men, from the time I was a young boy, I was taught not to cry. I was told that crying was a feminine characteristic, a sign of weakness. I knew that if I cried without having a very good reason, I would be subjected to teasing and name calling. While growing up, there were many times I wanted to cry, but I was afraid of what my male peers would think and say about me. As it turned out, I had to wait until I was 38 years old before I finally realized that it was all right to cry.

One day, early in our marriage, before our children were born, I arrived home to find my wife, Tina, in the living room sobbing. "Why are you crying?" I asked as I tried to console her.

"I don't know," she replied.

"What do you mean you don't know? How can I help if I don't know why you're crying?"

"I don't know, honey! I just feel like crying."

"That's ridiculous! You have to be crying for a reason. C'mon! What is it?"

"I don't know!" Tina answered.

I became very frustrated. I had expected to come home to a happy wife, a clean house, a nice dinner and maybe, a little romance. Instead I was met by a crying wife who had no reasonable explanation for her actions. I despaired of ever understanding women!

Hogan Hilling with wife Christina Ann and sons Wesley and Grant. At right, the boys with their new brother, Matthew.

One evening last year, I went through my usual bedtime ritual of going into my sons' rooms to kiss them good night as they slept. This was a special time each day when I felt as though I could stop the hands of time to cherish the privilege and honor of being a father. After I kissed Wesley, a warm feeling came over me that touched my heart like never before. His beautiful face, glowing in the dark night, brought tears to my eyes. I sat motionless on the edge of his bed, crying my eyes out.

Ten minutes later, my face still wet with tears, I walked to the master bedroom. I got into bed next to Tina, looking for comfort. She held me in her arms as I let out the biggest cry of my life. I was crying so loud that I thought the neighbors might hear. I put a pillow over my head to muffle the sound.

I cried for what must have been close to 30 minutes. Like a good wife, Tina did her best to console me. Then, it was time to for *her* to ask the infamous question, "Hogan, why are you crying?"

Guess what my answer was. That's right—"I don't know!"

When I look back to the first time I asked my wife that question, I can see how insensitive I was because

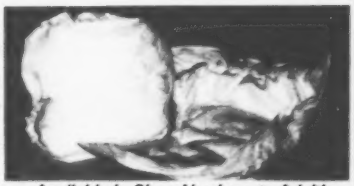
---

Hogan Hilling lives in Irvine, California, with his wife, Christina Ann, and three sons, five-year-old Grant, three-year-old Wesley, and eleven-month-old Matthew. Wesley has Angelman syndrome, a rare chromosomal disorder. Hogan is a founder, and member of the board of directors of the Fathers' Network of Orange County.

371

Finally Available!

All-In-One, Cotton Flannel
Adult Briefs... Comfort You Can Trust



Available in Sizes Newborn to Adult!

Adults everywhere with incontinent needs are telling us how thankful they are to have *finally* found a company with quality, reusable cloth adult briefs that work.

We're the *Friendly Earth Company* — specialists at producing the finest adult briefs you'll find anywhere. Our vast selection of reusable products not only provide comfort, convenience and save you money — but also preserve your dignity.

Our all-in-one adult briefs feature plush cotton layers inside, a waterproof nylon outer shell, and your choice of Velcro™ or snap closures (pull-on style briefs are also available). The soft elastic around the legs makes the brief leakproof.

Call for our **free catalog** and ask how you can obtain a sample adult brief.

Friendly Earth Company, Inc.

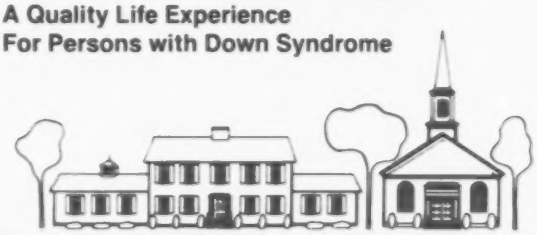
1-800-358-2128
1103 East 120 South • Spanish Fork, UT 84660

VISA

Circle # 153

Pathfinder Village

A Quality Life Experience
For Persons with Down Syndrome



In this picturesque colonial village, located in scenic central New York State, life is full of wholesome activities and rewarding opportunities. Residents with Down Syndrome experience the joy and personal satisfaction of learning, working, and participating in a vital, dynamic community. Our year-round, co-ed program includes education, recreation, and employment opportunities plus the chance to live life to the fullest. *Call us today.*

R.R. #1, Box 32-A, Edmeston, NY 13335
Telephone (607) 965-8377

Circle # 161

Hogan Hilling with sons Grant (left), Wesley (right) and Matthew.

of my frustration with her inability to answer. And although I didn't have an answer for her that evening, the next day I understood my reasons for crying. Crying helped me release all the tension, anxiety and frustration that had been building up inside me. It felt great to relieve myself, in a nondestructive way, of all the hurt and pain I was feeling. I also realized that I could never love another human being as much as I loved my children that night.

Crying is a wonderful, intimate experience that I recommend to any man. It's an experience men ought to learn to accept and share with their families. By coming to terms with my own need to cry, I now have a much better understanding of other people's feelings. Most importantly, it has strengthened and enhanced the relationship I have with my wife and children.

Put the macho stuff on hold for a while, guys. Find the strength within yourself to open up your heart and give yourself permission to cry, cry, cry for whatever reason. You'll be a better man because of it.

Fathers's Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth St., Bellevue WA 98008, (206) 747-4004; fax: (206) 747-1069. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda , MD.

From Rage to Reform: What Parents Say About Advocacy

by Judith A. Mayer

"We got on those committees because we were desperate for change. We have desperate crisis-oriented kids. We have to have change."

Although her child has a serious emotional/behavioral disorder, this mother, like many other parents of children with disabilities and chronic illnesses, has managed to overcome stigma and resistance from professionals and the public to become an advocate.

Bernard Cacho and his son Philip, 9, address the the U.S. House of Representatives Subcommittee on Health and the Environment. The Cacho family testified on President Clinton's proposed national health care plan and how it would affect people with disabilities and their families. Philip has cerebral palsy. Photo: Bruce Young/United Cerebral Palsy Associations.

"Not only are our children stigmatized—so are we!"

Anger progresses to rage. Parents become angry at professionals who blame them for "poor parenting" and will not listen to what they have to say about caring for their children. They are upset with the policies of educational and mental health systems that do not meet their children's needs.

Listening to Parents

I began listening to parents—first, as a parent of children with special emotional needs, then, as an associate with the Research and Training Center on Family Support and Children's Mental Health in Portland, Oregon. The Research and Training Center staff interviewed parents from across the United States, individually and in groups, about their advocacy experiences. Common themes were woven through their personal stories of parenting and advocating for children with emotional and behavioral disorders.

Parents are the first to realize that "something is different" about their child. This realization produces a variety of emotions—fear, guilt, shame, loss and grief. Parents spoke of the barriers to finding support and services:

- **Blame:** Parents are blamed for their child's disability—*"Blame either keeps us from getting involved, or makes us so angry that we get involved just to prove them [professionals] wrong."*
- **Stress:** *"Some days it is just exhausting to be with my child."*
- **Stigma:** *"It is the stigma of mental illness. You're not going to say to anyone, 'My child is driving me crazy.'"*
- **Lack of understanding:** Professionals do not understand—*"We were stereotyped as emotionally disturbed parents who had to be tolerated."*
- **Lack of services:** Educational and mental health services are often unavailable and/or inappropriate—*"Programs need to be designed for the needs of the children and the parents rather than for the needs of the bureaucracy."*
- **Lack of knowledge about resources:** *"We didn't know what help was available to us. Professionals did not know either."*

These parents knew that in order to make a better life for their child and family, they needed to overcome these barriers. Most started by contacting another parent who led them to a support group.

Help and Hope

Parents found that an invitation to join a support group was the most helpful ingredient on the road from anger

to advocacy. Parents who could not find a support group started one. Support groups provide a safe place to vent anger at both professionals and a service system that does not understand or meet the needs of their children.

Parents shared other factors that allowed them to overcome barriers:

- **Other parents:** *"Parents need special time to just be with other parents...to share strength together."*
- **Learning about resources and services:** *"I wanted to be informed about how I could help...These parents took the time to talk to me about my fears and anxieties. They said, 'You need to start looking for services and be your child's best advocate.'"*
- **A professional mentor:** *"A good professional is a gift."*
- **Success in getting services:** *"You begin to change things for your own child. Then you think, 'Maybe I can do this for more kids.' That's how I started as an advocate."*

From Personal To Public Advocacy

"Personal advocacy" occurs when a family overcomes barriers and successfully makes changes in a child's life. This experience often provides a springboard to move into public advocacy for other children. This transition from personal to public advocacy brings about needed improvements in services for children—*"When you start putting ideas together, you can make a difference. This time it will help my kid; next time it will help another kid."*

Parents who are not successful in finding services for their child can also become public advocates—*"Our involvement has evolved from being so overwhelmingly angry at a system that couldn't serve our child to deciding that we could vent our anger in a way that will change services—perhaps not in time for our child, but maybe other parents and other children will not have to suffer..."*

More than any other emotion, anger serves as the driving force for change. Dealing with personal anger and seeing it as a positive force for change has proven effective for parent advocates.

Advocacy Has Benefits—and Costs

Parents have found that joining with other parents brings benefits to themselves as well as to their child and other children.

"What's kept me going is being armed with so much information that I can share with so many other parents."

"...my advocacy brings about change that improves services not only for my kid, but also for kids across the state."

"Being able to change the system does something for my self esteem. I feel good about myself when I talk with other people who are struggling with the same issues."

Public and private advocacy ends isolation by providing opportunities to share experiences with other parents without blame or judgment. Parents assist each other in identifying needed services and accessing or advocating for these services. By helping others, parents feel valued for their experience and expertise.

Parents also begin to work with professionals to bring about attitudinal and system changes. Collaborating with professionals, they provide a unique perspective on the child and the disability.

But advocacy also has its costs: being both parent and advocate for one's child takes considerable time and commitment. Moving into public advocacy requires even greater commitment and may lead to greater frustrations.

"...as a parent on a committee, I am expected to answer for every parent."

"...it's so hard to sit at meetings and listen. I can't decide if I want to scream or cry."

"You have to fight a system that's unbelievable, and you get tired. We all need a break sometimes."

"I feel hopeless sometimes when I don't see that what I've said or done has made any difference."

"I feel intimidated by professionals."

"Professionals ask me questions but they never really listen."

"I have contributed to a lot of groups and have barely even gotten a 'thank you.'"

Although public advocacy has many difficulties, parents stay involved to bring children the services that will give them a brighter future. Many parents view their involvement as integral to the role of being a parent.

A Family Affair

A decision to move into public advocacy needs to be made by the entire family. Families need to decide on the extent of their involvement.

Public advocacy can involve time away from home; this places heavier responsibilities on other family members. Sometimes families just need to pull back and "recharge their batteries." When a child is doing well, parents may want simply to enjoy time together. A family may need to take a break.

Often, advocacy involves talking about private family experiences—*"It is hard to make a career of your child's disability; you keep living those events over and over."* A parent who is beginning to consider public advocacy needs to think about respecting the privacy of the child and family. They also should contemplate how, or whether other family members, including the child with a disability, should become involved—*"Children whose lives are emotionally disordered need the advocacy of those who parent them.*

They cannot do it themselves. As they grow older, it is the task of parents and professionals to help them learn how to advocate for themselves."

Words of Wisdom

Parents who advocate for improved services in education and children's mental health learn by trial and error. They continue because they see changes and because they believe in the power of parents. These parents advocate with compassion, strength and hope—*"Our role switched from one of saying, 'well, we just happen to be parents,' to... 'we have expertise that nobody else has.'"*

Parents who have "been there" offer this advice:

- Make decisions about public advocacy *as a family.*
- Define the roles family members will play in advocacy.
- Join with other parents in advocacy. Decide on the issues to be addressed; present a united front.
- Have a coach or mentor—usually a professional—to keep parents informed about system issues and politics.
- Have a team of parents available to serve on boards and other committees. Know the board you will serve on. Know your role on the board, the time commitment required and the provisions that have been made to reimburse you for expenses.

Advocacy Works

"What I gained a long time ago from other people, I can give away now. It's my gift to all parents."

The process of working through anger, hurt and frustration with other parents can lead to reforms in education and mental health services for children. The parents in this story found hope for the future by using anger as a force for change. A parent is a child's best advocate; you can make a difference.

Judith A. Mayer, MSW, is Project Coordinator for an integrated service center in a local high school. She is the parent of two teenagers who have special needs.

The Research and Training Center on Family Support and Children's Mental Health provides information to families of children with serious emotional disorders, as well as professionals and other interested persons. The National Clearinghouse on Family Support and Children's Mental Health includes a national toll-free telephone service, a computerized data bank, a series of information sheets on children who have emotional disabilities and their families, a state-by-state resource file and a family resource coordinator. Contact: The National Clearinghouse on Family Support and Children's Mental Health, Portland State University, PO Box 751, Portland, Oregon 97207-0751, (800) 628-1696.

Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Associations with leading specialists and major medical centers

Affiliation with SUNY

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

Circle #6

Racing Wheelchairs for Children

By Alynne Landers

Wheelchair racing is fun, recreational, therapeutic and highly competitive. Adults don't have all the fun, though—kids, too, are tearing up the tracks. Within the junior class, the girls are as tough as the guys—the 1992 and 1993 *Sports 'n Spokes* Junior Athletes of the Year, Shannon Morrisey and LeeAnn Shannon, are racing champions.

As with all sports and recreational activities, safety considerations should be foremost. It is advisable that a protective helmet be worn at all times while racing.

Racing champion LeeAnn Shannon races in the Top End Eliminator, manufactured by Top End by Action, Pinellas Park, FL.

From the standard wheelchair to today's state-of-the-art models, the racing chair has gone through many changes: its seat angle has been raised to provide better sitting stability; the seat itself has been lowered; the two widespread front casters have been replaced by one large tire, and the front housing, connecting the front wheel to the frame, has been extended to create an open V-shaped form or a single bar, an "I" or "T" frame. Today's aerodynamic chairs have a lower center of gravity, provide a more stable seat for the racer and are incredibly fast.

Racing Wheelchair Components

Scaled down to proportionate size, children's racing wheelchairs have the same design as those for adults.

- *Seats* come as variations on one of two forms. The first looks like a standard wheelchair seat but with a shorter depth and a fabric strap which attaches to either side of the seat frame to go over or in front of the knees. This is sometimes referred to as a traditional seating position.

The second style is the bucket seat that supports the lower legs from the knees to the ankles. This seat keeps the legs in a tucked position under the racer's torso, resulting in the "kneeling" racing position.

- *Frames* are generally tubular and made of chrome-moly, graphite or other lightweight composite materials. The more aerodynamic V-shaped frame consists of one or more sets of bars that connect to a center bar or the front wheel housing from each side of the seat. This style is designed for advanced racers who have the flexibility to transfer over side bars and assume a kneeling position.

"I" or "T" frames feature a single straight bar extending to the front wheel housing from underneath the racer's seat. This style allows easier transfers and may be better for quadriplegics or beginners.

Frames range in length from about 30 to 52 inches for children, and 50 to 56 inches for youth. A handbrake is located near the front wheel casing on the center frame bar, along with a track compensator or steering system. The steering system may provide the ability to "lock-in" a steering position such as a constant turn or straightaway so the racer may concentrate more on propulsion than steering.

Quickie Shadow Racer, Quickie Designs/Shadow Products, Kent, WA.

- *Rear wheels* usually measure 24 or 26 inches; *front wheels* are 16 or 20 inches for children and youth. Some models have a "fender" running over the top portion of the rear tires to prevent chafing on the inside of a racer's arms. Handrims, or pushrims, on the rear wheels range from 13 to 16 inches; the optimum diameter is determined by what is most comfortable for the individual racer.
- A variety of *footplates* have been developed for various abilities and preferences. A fixed platform may be best for children who have difficulty transferring or strapping in their feet. For others, a simple foot strap may be sufficient.

Accessories

While standard equipment will get your child to the finish line, there are many available accessories to help racers do it more efficiently. *Push-gloves* help to protect the hands and may give better traction for each push. *Safety lights* may be added for higher evening visibility, and *water bottles* or *drinking sys-*

MANUFACTURERS OF RACING WHEELCHAIRS FOR CHILDREN

Brookes Products
527 Casitas Rd
Santa Barbara, CA 93103
(805) 965-3530

Eagle Sportschairs
2351 Parkwood Rd
Snellville, GA 30278
(404) 972-0763

Fortress
827 Jefferson Ave
Clovis, CA 93612
(800) 866-4335

Hall's Wheels
PO Box 380784
Cambridge, MA 02238
(617) 628-7955

Olympian Wheelchairs
7830 38th Ave N, Unit #1
St Petersburg, FL 33710
(813) 343-8375

Quickie Designs/ Shadow Products
20604 84th Ave S
Kent, WA 98032
(800) 342-1579

Top End by Action
4501 63rd Circle N
Pinellas Park, FL 34665
(800) 532-8677

376

tems can help a racer keep cool. *Tool kits* are handy for dealing with minor mishaps, and *cordless computers* assist in race training. *Side guards*, which protect a racer's clothing from entering the spokes of the rear wheels, may be standard or optional equipment.

As far as appropriate racing wear is concerned, anything goes! For recreational racing, anything comfortable will do—however, clothing should not be too loose or include belts or scarves which might tangle in the rear wheels. Competition racing outfits are colorful and diverse. Form-fitting body suits are becoming the norm in competitions worldwide. Shoes, however, are more often than not left on the sidelines. For reduced weight and wind resistance, most racers wear only socks or go barefooted during workouts or competitions.

Competitions

Young racers can pit their abilities and equipment against one another and the clock at local, regional, national and international competitions. Children are allowed to compete in marathons along with adults, but there are also many events specifically for children that are held in conjunction with adult events. For kids only, the Junior National Wheelchair Championships are held annually in the United States; comparable events are held in many foreign countries.

More information on competitive events is available from: National Handicapped Sports (Rockville, MD, 301/217-0960), Wheelchair Sports, USA (Colorado Springs, CO, 719/574-1150) and International Wheelchair Road Racers Club (Stamford, CT, 203/967-2231).

Alynne Landers, M.I.M., is a Program Specialist at ABLEDATA, the government-funded project which maintains the assistive technology database by the same name. The database lists more than 19,000 products for persons with physical, cognitive and/or sensory disabilities. The project is managed by Macro International Inc. for the National Institute on Disability and Rehabilitation Research (contract no. HN92026001).

At Devereux . . .
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

NEW! from
The Advocado Press

A handy manual for parents, advocates, caregivers, staffpersons, volunteers, for anyone who believes that adults labeled severely and profoundly retarded can both enjoy and contribute to a full, meaningful life in our communities. A fresh and practical approach to all aspects of organizing and operating an exemplary community-based daily living program.

Compact but thorough, **Agenda for Real Life** includes:

-Physical requirements for a site,

-A variety of sources for funding,

-A natural basis for planning and scheduling,

-Guidelines for meaningful adult activities.

A book to use every day as a convenient, indispensable source of ideas.

Order from:
The Advocado Press, P.O. Box 145, Louisville, KY 40201
1 copy $8.95, 2-4 copies $8.25 each, postage paid if you mention this ad.
For discounts on larger quantities, call (502) 459-5343.
Checks payable to The Advocado Press. Allow 6-8 weeks for delivery.

RECREATION

Resources

The following national organizations sponsor recreational events and/or provide information about recreation programs for people with disabilities. Groups listed in the general recreation category can provide information and referrals for a number of recreational activities, including many for which there is no national organization.

RECREATION (GENERAL)

American Athletic Association of the Deaf
3607 Washington Blvd, Ste 4
Ogden, UT 84403-1737
(801) 393-8710 (Voice)
(801) 393-7916 (TTY)
(801) 393-2263 (FAX)
all ages, deaf and hard of hearing; referrals to local groups, annual children's sports festival

Boy Scouts of America Scouting for the Handicapped Service
1325 W Walnut Hill Ln
Irving, TX 75038
(214) 580-2000
referrals to local troops

Canadian Wheelchair Sports Association
1600 James Naismith Dr
Gloucester, ON
CANADA K1B 5N4
(613) 748-5685
(613) 748-5722 (FAX)
all ages; referrals to local groups, national programs

Girl Scouts of the USA Services for Girls with Disabilities
420 5th Ave
New York, NY 10018
(212) 852-8000
(212) 852-6515
referrals to local troops, training for scout leaders

International Center on Special Recreation
c/o John Nesbitt
362 Koser Ave
Iowa City, IA 52246-3038
(319) 337-7578
all ages, all disabilities; referrals to local groups, information on recreational activities

National Handicapped Sports
451 Hungerford Dr, Ste 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0968 (FAX)
ages 5 and older, all physical and developmental disabilities; referrals to local groups, parent advocacy training

Sam Warmann cools off at the 1993 Wheelchair Sports, USA Junior Nationals. Photo: Curt Beamer, SPORTS 'N SPOKES/ Paralyzed Veterans of America, 1993.

U.S. Association for Blind Athletes. Photo: Eric Horan.

National Sports Center for the Disabled
PO Box 36
Winter Park, CO 80482
(303) 726-5514
(302) 892-5823 (FAX)
all ages, all disabilities; referrals to local groups, national programs

Wheelchair Sports, USA (National Wheelchair Athletic Association)
3595 E Fountain Blvd, Ste L1
Colorado Springs, CO 80910
(719) 574-1150
ages 5 and older; referrals to local groups, national office for various sports

US Association for Blind Athletes
33 N Institute St
Colorado Springs, CO 80903
(719) 630-0422
all ages; local, national and international sports events

US Cerebral Palsy Athletic Association
500 S Ervay St, Ste 352B
Dallas, TX 75220
(214) 352-4100
ages 6 and older, cerebral palsy and related conditions; referrals to local groups

BASKETBALL

National Wheelchair Basketball Association
c/o Stan Labanowich
Univ of Kentucky
110 Seaton Bldg
Lexington, KY 40506
(606) 257-1623
(606) 258-1090 (FAX)
teenagers with mobility impairments; referrals to local groups

BOWLING

Wheelchair Bowling Association
c/o Walter Roy
3620 Tamarack Dr
Redding, CA 96003
(916) 243-2695
all ages; referrals to local groups, information

FISHING

Fishing Has No Boundaries
PO Box 175
Hayward, WI 54843
(715) 634-3185
all ages, all disabilities; fishing events

GARDENING

American Horticultural Therapy Association
362A Christopher Ave
Gaithersburg, MD 29879
(301) 948-3010
(301) 869-2397 (FAX)
all ages, all disabilities; referrals to local groups, employment program

HOCKEY

American Sledge Hockey Association
c/o John Schatzlein

FEEL N' TWIST™

.....a game for **everyone!**

Sportime Abilitations' **FEEL N' TWIST** is an original tactile game for players of all ages and abilities.

Though originally designed by an adaptive specialist for her visually impaired students, **FEEL N' TWIST** can also be played by those with other physical, mental, and auditory impairments. It features raised foam shapes that attach to a vinyl mat via Velcro®. This movable configuration enables teachers and parents to modify games each time they're played. The game is available with standard text or durableplastic Braille cards to guide play.

Benefits of playing include improved coordination, motor planning, reading, tactile skills and group participation.

15581202-E4 FEEL N' TWIST. With plastic Braille cards.....**139.95 ea.**
15580202-E4 FEEL N'TWIST. With Standard text on card weight stock.....**69.95 set**

SPORTIME Abilitations

To order **FEEL N' TWIST** or a free **ABILITATIONS** catalog loaded with products for special needs populations

1-800-283-5700 Dept. #AADI9

Circle # 189

10933 Johnson Ave S
Bloomington, MN 55437
(612) 750-3973
teenagers with mobility impairments; referrals to local teams

HORSEBACK RIDING

North American Riding for the Handicapped Association
PO Box 33150
Denver, CO 80233
(800) 369-7433
(303) 452-1212
all ages, all disabilities; referrals to local groups

PERFORMING ARTS

Association for Theatre and Disability
c/o Access Theatre
527 Garden St
Santa Barbara, CA 93101
(805) 564-2063
(805) 564-2424 (TTY)
(805) 564-0051 (FAX)
all ages, all disabilities; referrals to local groups

Very Special Arts
1331 F St NW, Ste 800
Washington, DC 20004
(202) 628-2800
(202) 737-0645 (TTY)
all ages, all disabilities; referrals to local branches, programs in drama, dance, creative writing, literature, music and the visual arts

ROAD RACING

International Wheelchair Road Racers Club
c/o Joseph M. Dowling
30 Myano Ln
Stamford, CT 06902
(203) 967-2231
(203) 327-7999 (FAX)
all ages; referrals to local groups

SKIING

Canadian Association for Disabled Skiing
Box 307
Kimberley, BC
Canada V1A 2Y9
(604) 427-7712
(604) 427-7715 (FAX)
all ages, all disabilities; referrals to local groups, information

SOFTBALL

National Wheelchair Softball Association
c/o Jon Speake
1616 Todd Ct
Hastings, MN 55033

The Bonfils-Stanton Winter Park Outdoor Center in Winter Park, Colorado, provides a universally-accessible trail system for hiking, camping and fishing to participants in summer programs sponsored by the National Sports Center for the Disabled. Photo: Jeff Stine.

(612) 437-1792
referrals to local groups, 30 teams nationwide

TENNIS

National Foundation of Wheelchair Tennis
940 Calle Amanecer, Ste B
San Clemente, CA 92672
(714) 361-6811
ages 7 and older; referrals to local groups, annual camp, national and local tournaments

WATER SPORTS

American Water Ski Association
c/o Phil Martin
Adaptive Aquatics
PO Box 21
Jackson Gap, AL 36861
(205) 825-9091
(205) 825-8332 (FAX)
all ages, all disabilities; referrals, information

Canadian Wheelchair Sports Association
Committee for Sailors with Disabilities
1600 James Naismith Dr
Gloucester, ON
Canada K1B 5N4
(613) 748-5685
(613) 748-5722 (FAX)
all ages, all disabilities; referrals to local groups

US Wheelchair Swimming
c/o Larry Quintilani
229 Miller St
Middleboro, MA 02346
(508) 946-1964
ages 7 and older; referrals to local groups, recreational and competitive swim programs

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle #75

CHILDREN'S CARE HOSPITAL & SCHOOL

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1000 children with disabilities and their families each year. CCHS offers individualized, family-centered programs through day school, outpatient, outreach, or residential services.

Contact: Nathan Anderson
Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840 or (800) 584-9294

Special Force Family Ministries

A PLACE TO CALL HOME
Special Force Family Ministries operates superior quality residential programs for adults with mental retardation in private homes near Minneapolis, MN and Springfield, MO. Residents become members of individual families where Christian values are affirmed. Community involvement. Recreational opportunities. Affordable rates. Established 1973. Call for details.

Contact:
Special Force Family Ministries
P.O. Box 47, Waconia, MN 55387
(612) 442-4441

Annandale Village

Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

TENNESSEE
TALL PINE CAMP
Exceptional Citizens
SINCE 1969

TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available.

Contact: Ron & Cammie Eydt
Tall Pine Camp
114 Tall Pine Circle
Tellico Plains, TN 37385
(615)261-2329/(615) 261-2138

Camp Huntington
33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

Special Olympics State Chapters

Special Olympics participation is open to individuals who are more than five years of age, and who have mental retardation or cognitive delays. Children may begin participating in Special Olympics competitive events at the age of eight.

This spring and summer, Special Olympics state games will be conducted by all 51 state chapters. Prior to state games, athletes will compete in local or area competitions that will take place in more than 1,500 sites around the country. Athletes will compete in such sports as swimming, softball, running, equestrian events and bowling. For more information on Special Olympics events in your area, contact your state's chapter. (Phone numbers listed are for voice only.)

More than 450,000 athletes will take part in Special Olympics competitions this year; some will have the opportunity to represent Team USA at the 1995 Special Olympics World Summer Games in New Haven, Connecticut. For more information on the World Summer Games, contact: Special Olympics International Headquarters, 1350 New York Ave, NW, Ste 500, Washington, DC 20005-4709, (202) 628-3630, Voice only.

ALABAMA
880 S Court St
Montgomery
AL 36104
(205) 242-3383

ALASKA
21-410 2nd St
Elmendorft
AK 99506
(907) 333-7006

ARIZONA
3821 E Wier Ave
Phoenix, AZ 85040
(602) 470-1080

ARKANSAS
1123 S University,
Ste 1017
Little Rock, AR 72204
(501) 666-0423

CALIFORNIA
501 Colorado Ave,
2nd Fl
Santa Monica
CA 90401
(310) 451-1162

COLORADO
1400 S Colorado Blvd,
Ste 400
Denver, CO 80222
(303) 691-3339

CONNECTICUT
50 Whiting St
Plainville, CT 06062
(203) 747-5338

DELAWARE
Hudson Ctr
501 Ogletown Rd,
Rm 123
Newark, DE 19711
(302) 368-6818

WASHINGTON, DC
220 Eye St NE,
Ste 140
Washington, DC
20002
(202) 544-7770

FLORIDA
2639 N Monroe St,
#151A
Tallahassee
FL 32303
(904) 385-8178

GEORGIA
3772 Pleasantdale Rd,
Ste 195
Atlanta, GA 30340
(404) 414-9390

HAWAII
1085 S Beretania St,
Ste 200
Honolulu, HI 96814
(808) 531-1888

IDAHO
8426 Fairview Ave
Boise, ID 83704
(208) 323-0482

ILLINOIS
605 E Willow
Normal, IL 61761
(309) 888-2551

INDIANA
5648 W 74th St
Indianapolis
IN 46278
(317) 328-2000

IOWA
4921 Douglas, Ste 1
Des Moines, IA 50310
(515) 278-2513

KANSAS
5830 Woodson, #106
Mission, KS 66202
(913) 236-9290

KENTUCKY
214 W Main St
Frankfort, KY 40601
(502) 227-7296

LOUISIANA
200 SW Railroad Ave
Hammond, LA 70403
(504) 345-6644

MAINE
28 School St
Gorham, ME 04038
(207) 839-6030

MARYLAND
5020 Campbell Blvd,
Ste F
Baltimore, MD 21236
(410) 931-4100

MASSACHUSETTS
PO Box 303
Hathorne, MA 01937
(508) 774-1501

Continued on page 64

The Next Step Up In Wheelchair Mobility.

You're looking at scalamobil,™ a remarkable system designed to take on the toughest stairs. Fully automatic safety brakes. Only 42 pounds, it's half the weight of other systems. Folds to the size of a large briefcase.

For more about scalamobil and other alber® products, call and find out what's next.

TMI TECHNOMARKETING INC

©1994 TMI

307 Bacon Road • Rougemont North Carolina 27572 • (919) 477-1387 • Fax (919) 477-2294

Circle # 178

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: CRI
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle # 162

Bundle Hug'r

... helps keep an exceptional child's legs in place and warm by completely wrapping them comfortably. Two styles available.

Fully assembled in the United States with U. S. materials. Quality workmanship. Carefully inspected.

Kotton Koala **... more than a hug!**

P.O. Box 178 • Fort Jones, CA 96032

(916) 468-5475 FAX: (916) 468-5492

Circle # 191

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106.

EXCEPTIONAL PARENT

120 State Street
Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)
Fax (201) 489-1240

Vice President Advertising Sales
KERRY J. CANNON

Sales Representatives

BARBARA NASTRO
New England, East Canada,
DE, DC, MD, NJ, NY, PA, VA, WV
Schools, Camps, Residences, Classified & Special Sales
(201) 680-4874
(201) 680-8355 Fax

WILLIAM MIDDLETON
Southeast (AL, FL, GA, KY, MS, NC, SC, TN)
(404) 973-9190
(404) 565-7013 Fax

ANTHONY ARNONE
Midwest (IN, KS, MN, ND, OH, SD, UT, CO)
(708) 428-5162 Phone and Fax

JOHN MAISEL
Midwest (IL, IA, NB, MI, MO)
(708) 416-0780
(708) 416-0793 Fax

JANE HAYWARD
Southwest (AR, AZ, LA, NM, OK, TX)
(714) 366-8455
(714) 366-9289 Fax

RICHARD AYER
West Coast (So CA, NV)
(714) 366-9089
(714) 366-9289 Fax

WILLIAM HAGUE
West Coast (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
(206) 858-7575
(206) 858-7576 Fax

Ad Traffic Manager
STEFANIE FERRANTE
120 State Street
Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)
Fax (201) 489-1240

BPA International Consumer Magazine Membership Applied for August 1993.

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
	Apple Computer	21
170	Aquatic Therapy	46
6	Berkshire Meadows	51
7	BHC-JA Preston	C4
8	Bruno	35
190	Care Concepts	17
10	Charles C. Thomas	27
185	Children's Specialized Hospital	30
186	Civitan International	18
11, 12	Columbia Medical	25, 45
145	CompCare	18
16	Convaid	C3
14	Crow River	13
18	Cumberland Hospital	32
19	Devereux	53
	Disability Rag	53
25	Equipment Shop	18
26	Estate Planning	18
	Exceptional Parent Library	66, 67
27	Evergreen	6
174	Family Clubhouse	46
30	Ford	C2
153	Friendly Earth	48
187	Hanen Program, The	30
39	HMS School	37
36	Haverich Ortho-Sport, Inc.	14
38	Heartspring	40
40	Homecare Products	64
42	Innovative Products	31
44	Jay Medical	3
46	Kid-Kart	15
191	Kotton & Koala	58
48	Laureate Learning	37
176	Morris Corn	62
168	Merrill Lynch	5
52	Mulholland	6
161	Pathfinder Village	48
123	PI Bear	20
66	Rifton	26
67	Rollins Healthcare	34
75	St. John's Villa	56
68	Sentient Systems	7
69	Snug Seat	39
189	Sportime	55
76	Starlight Footwear	7
78	Stroller Pak	31
120	Teledyne Brown	41
122, 178	TMI	26, 57
82	Triaid	44
188	Whitmyer Biomechanix	37
162	Willow River Farms	57
86	Woodbury Products	44

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: May 31, 1994

Expiration Date: August 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: May 31, 1994

Expiration Date: August 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

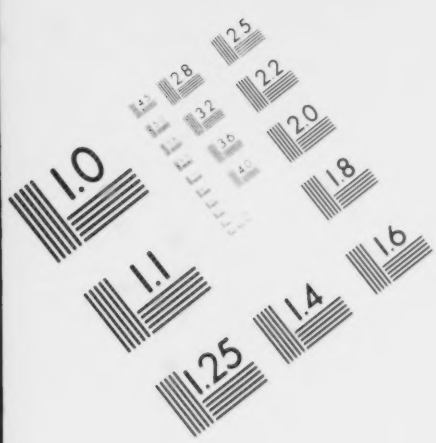
BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

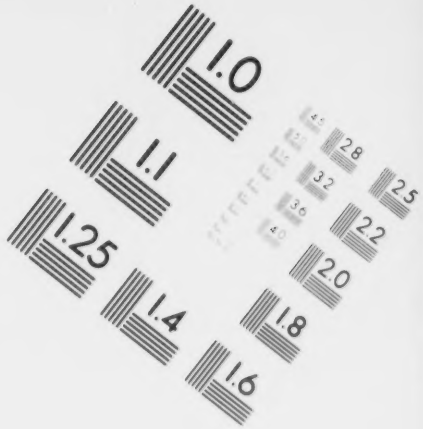


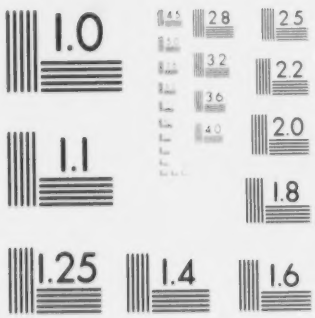
AIIM

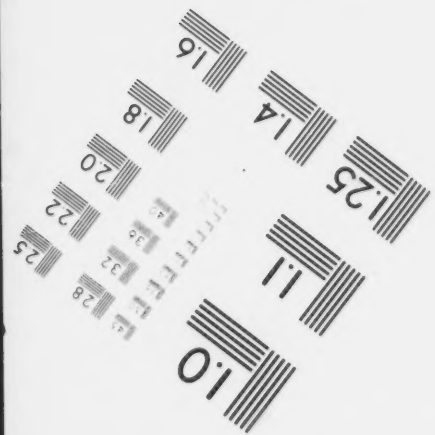
Association for Information and Image Management

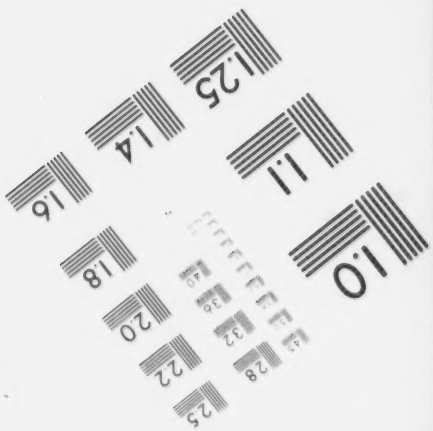
1100 Wayne Avenue, Suite 1100
Silver Spring, Maryland 20910

301/587-8202









MANUFACTURED TO AIIM STANDARDS
BY APPLIED IMAGE, INC.

Market Place

Bibs

Ross' Bibs
Haco, Inc.
PO Box 5642, Asheville, NC 28813
(704) 274-0075
These Bibs were originally made for our son, Ross, by his Aunt Catherine. Now we can make them for your special child. They are made of machine washable, long lasting, heavy duty vinyl. The large child size is $13.95. The teenage/small adult size is $15.95; plus $2.00 shipping. Other sizes available, please call for more information.

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Clothing

Richman Cotton Company
100 % Cotton Clothing & Blankets
Easy to dress. Easy to see.
FREE Catalog. 800-992-8924

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical
Spring Savings on ALL Strollers—Equipment and Supplies Discounted to 50%. Call 800-877-9100. Free brochure.

Florida

Home Medical Equipment Co.
2137 Fowler Street
Ft. Myers, FL 33901
(800) 226-0404
Custom wheelchairs and seating for pediatric to geriatric. On-site repair center. Rental of most medical equipment and vans.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New Hampshire

Advent Medical/Ride-Away
51 Wentworth Ave.
Londonderry, NH 03053
(603) 437-4444
Advent Medical specializes in all types of rehabilitation & mobility equipment for your child. Nurse & therapist on staff for any positioning issues. Dealers of all major brands of equipment. Skilled technicians, 24 hour everyday service. Huge list of references available.

New York

Rehabco
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in children's mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Free Catalogs

Consumer Care Products, Inc.
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted.
Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Mobility

Blue Sky Cycle Carts
PO Box 5788
Bend, OR 97708
(503) 383-7109
Enjoy cycling with the whole family. We offer customized bicycle trailers adapted to carry children & adults with special needs.

Monitoring Systems

Care Electronics
5741 Araphoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Sign Language

Evergreen Sign Language Gifts
PO Box 20003
Alexandria, VA 22320
(703) 683-3755 Call/Fax
Unique Sign Language Gifts for special friends; say "I Love You." Good fund-raisers too! Jewelry, Stationery, Clothing, FREE Brochure.

Toys & Hobbies

TFH (USA) LTD.
4449 Gibsonia Road
Gibsonia, PA 15044
(412) 444-6400
FREE CATALOG! Fun and achievement products for children with special needs. Call or write for more information.

Books, Audio/Video & Educational Material

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word.
Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Publications

Hydrocephalus News/Notes
Published quarterly for individuals/families & professionals who specialize in their care. Highlights: medical/technical articles, human interest stories, great resources! A. Liakos, Editor, HNN, 1670 Green Oak Circle, Lawrenceville, GA 30243. $25 year.

Let them know you saw their ad in EXCEPTIONAL PARENT!

To place an ad, please contact:
Barbara Nastro
EXCEPTIONAL PARENT
(201) 680-4874
Fax: (201) 680-8355

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Florida

Ocean Conversion & Mobility, Inc.
750 East Sample Road
Bldg. 8/#7
Pompano Beach, FL 33064
(305) 942-6033
Helping you meet your mobility needs. Total vehicle conversions. Certified Dealer/All Major Mobility Manuf. Customer assistance program. Member NMEDA.

Illinois

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Indiana

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Hampshire

Ride-Away Corp.
51 Wentworth Ave.
Londonderry, NH 03053
(603) 427-4444
The most complete line of new & used adaptive equipment for vehicles in New England. Lifts, ramps, wheelchair securements, new/used vans, trade-ins, financing available. 24 hours everyday. Service, healthcare professionals on staff.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tennessee

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. Call for more info.

CORN ASSOCIATES

Child Care/the education connection

An uniquely qualified firm and leading advisor to corporate human resource management personnel. Corn Associates is foremost a diversified pool of professional talent and academic practitioners who become the corporation's personal child care planners and providers.

- Child care consultants
- Experienced in knowledge of developmental grouping
- Personnel level advisor to corporate leadership on current educational trends

For more information write or call:

Corn Associates
P.O Box 298
Rochelle Park, NJ 07622
Phone: (201) 996-0720

Circle # 176

BEAT THE HEAT!
- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy

800-795-2392

DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

Made in USA Pat. 5168889 *Providing Comfort to Those Who Want It!*

386

WHAT'S HAPPENING

Friends Who Care

The National Easter Seal Society's *Friends Who Care*® disability awareness program was introduced in 20,000 elementary schools nationwide in the fall of 1990. By providing materials that help children better understand what it means to have a disability, this award-winning program teaches them to accept and include people with disabilities in their everyday lives.

Friends Who Care has been featured on NBC's *Today Show* and in *USA Today*, *Child Magazine*, *Weekly Reader* and local publications nationwide. The teaching materials and public service advertisements have won nine national awards.

The curriculum kit includes a pre- and post-program attitude survey, a 16-page teacher's guide with information and classroom activities designed to provoke hands-on experiences for children, five activity worksheets, a 45-minute video to augment the activities, guest speaker guidelines, five campaign posters and 50 bookmarks with tips on disability etiquette.

To order, send a $25.00 check or money order (includes postage/handling) to: National Easter Seal Society, Friends Who Care, 230 West Monroe St., Suite 1800, Chicago, IL 60606. For further information, call (312) 726-6200.

Camp for Kids with Vents

The PA Vent Camp is designed to provide a camp experience, free of charge, for medically stable children who are ventilator-dependent. This year's session will be held June 26–July 1 at Camp Harmony Hall in Middletown, PA. The camp is staffed by a team of health care professionals and community volunteers. Applications are still being accepted from children between the ages of three and eighteen. For more information, contact PA Vent Camp, P.O. Box 60443, Harrisburg, PA 17106, (717) 671-0226.

Support Groups

• The Autism and Sensory Impairments Network maintains a database of families with a member who has *autism and hearing or vision impairment*, and professionals who have an interest and/or experience with this combination of disabilities. For more information, contact Dolores and Alan Bartel, 7510 Oceanfront Ave., Virginia Beach, VA 23451, (804) 428-9036.

• A new support group is being formed for the families of children affected by *Rasmussen syndrome*. For more information, contact Al and Lynn Miller, 8235 Lethbridge Rd., Millersville, MD 21108, (410) 987-5221.

• A support group is being formed for the parents of children with *Opitz-Frias syndrome*, also known as Opitz-G syndrome or BBB syndrome. Major indications of this syndrome are extensive swallowing problems and hypospadius in boys or imperforate anus in girls. For more information, contact William and Janet Wharton, P.O. Box 516, Grand Lake, CO 80447, (303) 627-8935.

• FOCUS (For Our Children's Unique Sight) is a support network for families of children with rare visual disorders, including *septo-optic dysplasia* and *optic nerve hypoplasia*. For more information, contact FOCUS, 1583 Black Eagle Dr. D, San Diego, CA 92126, (619) 271-8488.

• A new network is being formed for parents of children with *opsoclonus-myoclonus syndrome*. For more information, contact Connie Quinn, 725 North St., Jim Thorpe, PA 18229.

• A support group has been formed for parents of children with *Aarskog syndrome*. The group, formed by the mother of two children affected by the syndrome, offers information and a newsletter. Contact Shannon Caranci, 62 Robin Hill Lane, Levittown, PA 19055-1411.

• A parent advocacy group, the FRAXA Research Foundation, has been formed by parents of children with *fragile X syndrome*. For more information, contact FRAXA Research Foundation, P.O. Box 935, Newburyport, MA 01985, (508) 462-1990.

• Forward Face, a support group for people and families with *craniofacial disorders*, publishes a quarterly newsletter that offers helpful, inspiring articles by parents, children and professionals. A membership to Forward Face, which includes a subscription to the newsletter, costs $15. Contact Forward Face, 317 East 34th St., New York, NY 10016, (800) 422-3223.

Publications

• *Iceberg* is a quarterly newsletter dealing with fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE). It is available from FAS Information Service, P.O. Box 95597, Seattle, WA 98145-2597, and costs $10/year for families; $20/year for professionals (prepaid subscriptions only).

• Two free booklets can help pre-college- and college-age students with disabilities make decisions about attending college and choosing a career. The booklets, *Find Your Future* and *You're in Charge*, are available from the American Association for the Advancement of Science, 1333 H St., NW, Washington, DC 20005, (800) 222-7809, V/TTY; (202) 371-9849, fax. Ask for AAAS publications 94-12S and 94-13S.

• *Developing Social Skills: Issues for Adolescents with Chronic Illnesses and Disabilities* is a bibliography of programs and materials that are available to help adolescents deal with relationships. A companion to this bibliography, dealing with self esteem, will soon be available. Cost is $6.00, available from University of Minnesota–NYCYD, Box 721, University of Minnesota, Minneapolis, MN 55455, (612) 626-2825.

• *Understanding Neurofibromatosis; An Introduction for Patients and Parents* is available from the organization Neurofibromatosis, Inc., Mid-Atlantic, 885 Annapolis Rd., Ste. 110, Lanham, MD 20706-2924, (301) 577-8984. Single copies are free.

• *Bone Marrow Transplants: A Book of Basics for Patients* is a 157-page book written by bone marrow transplant patients with the help of medical specialists. The book is designed to augment the information provided to patients and to translate medical terminology into lay language. Cost is $5.00; available from BMT Newsletter, 1985 Spruce Ave., Highland Park, IL 60035, (708) 831-1913.

SPECIAL OLYMPICS *continued from page 57*

MICHIGAN
Central Michigan University
Mt Pleasant, MI 48859
(517) 774-3911

MINNESOTA
625 4th Ave S, #1430
Minneapolis
MN 55415
(612) 333-0999

MISSISSIPPI
Southern Station
Box 5174
Hattiesburg
MS 39406-5174
(601) 264-7295

MISSOURI
1907 William St
Jefferson City
MO 65109
(314) 635-1660

MONTANA
3300 3rd St NE
Great Falls
MT 59404
(406) 791-2368

NEBRASKA
5021 S 24th St
Box 7569
Omaha
NE 68107-0569
(402) 731-5007

NEVADA
3160 S Valley View,
Ste 106
Las Vegas, NV 89102
(702) 222-1924

NEW HAMPSHIRE
650 Elm St
Ste 101
Manchester
NH 03101-2508
(603) 624-1250

NEW JERSEY
242 Old New Brunswick Rd
Piscataway, NJ 08854
(908) 562-1500

NEW MEXICO
6600 Palomas NE,
Ste 207
Albuquerque,
NM 87109
(505) 856-0342

NEW YORK
Airport Park
3 Cornell Rd
Latham, NY 12110
(518) 786-8661

NORTH CAROLINA
PO Box 98209
Raleigh
NC 27624-8209
(919) 878-7978

NORTH DAKOTA
2616 S 26th St
Grand Forks
ND 58201
(701) 746-0331

OHIO
3303 Winchester Pike
Columbus
OH 43232
(614) 239-7050

OKLAHOMA
6835 S Canton Ave
Tulsa
OK 74136-3433
(918) 481-1234

OREGON
3325 NW Yeon Ave
Portland
OR 97210-1525
(503) 248-0600

PENNSYLVANIA
124 Washington Sq
2570 Blvd of the Generals
Norristown, PA 19403
(215) 630-9450

RHODE ISLAND
33 College Hill Rd, #31
Warwick
RI 02886
(401) 823-7411

SOUTH CAROLINA
2615 Devine St
Columbia
SC 29205
(803) 254-7774

SOUTH DAKOTA
4200 S Louise Ave,
#201
Sioux Falls
SD 57106
(605) 361-2114

TENNESSEE
112 21st Ave S,
Ste 101
Nashville, TN 37203
(615) 322-8292

TEXAS
11442 N Interstate 35
Austin, TX 78753
(512) 835-9873

UTAH
4 Triad Ctr, Ste 105
Salt Lake City,
UT 84180
(801) 363-1111

VERMONT
5 Ave D
PO Box 1055
Williston, VT 05495
(802) 863-5222

VIRGINIA
100 W Franklin St,
Ste 400
Richmond, VA 23220
(804) 644-0071

WASHINGTON
2150 N 107th Ave,
Ste 220
Seattle, WA 98133
(206) 362-4949

WEST VIRGINIA
914 Market St,
Ste 201
Parkersburg,
WV 26101
(304) 422-1868

WISCONSIN
5900 Monona Dr,
Ste 301
Madison, WI 53716
(608) 222-1324

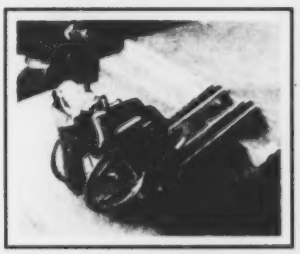
WYOMING
615 S David
Casper, WY 82601
(307) 235-3062

GUAM
970 S Marina Dr, #10
PO Box 203
Tamuning, Guam
96911
(011-671) 646-2566

EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

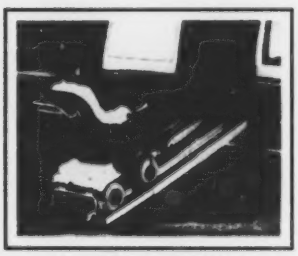
Look for this Seal of Quality



R1000 5' Portable Ramp

- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633
FAX 206-630-8196

Circle # 40

388

NEW PRODUCTS

LET'S GO TO THE CIRCUS

Animals, clowns, jugglers and *language development?* Yes! This program for the Apple IIGS or IBM computer combines large, colorful graphics with more than 75 vocabulary words and 20 pairs of opposites. This program is accessible with a keyboard, touch screen, single switch or mouse, and utilizes high quality speech to provide auditory reinforcement to visual learning.

Laureate Learning Systems, Inc., Winooski, VT 05404-1898

Circle # 192

WOODCRAFT CREATIONS ADAPTABLE HOBBYHORSE

The age-old classic hobbyhorse meets present day accessibility needs in this recreational and therapeutic toy. Hand-crafted of hardwoods, a stately steed with bridle and saddle sits atop a wide, reinforced rocking platform. A removable adapter frame developed for a child with severe disabilities fits over the horse and secures to the platform. The child can rock back and forth and exercise the legs and arms while being supported on all sides.

Woodcraft Creations, Salem, MO 65560

Circle # 193

FORMBOARD WITH A BRAIN

Microprocessor-controlled, extra-large shapes, angled play surface and tactile, auditory and visual feedback all in one product! This versatile activity board can be used for recreational play or entertaining therapy to teach cause and effect, fine motor skills, hand-eye coordination, spatial concepts and more. Sequencing activities can also be programmed. Correctly-performed activities are rewarded with internal tones, small vibrations, music and lights or moving toys when connected to the unit.

Enabling Devices, a division of **Toys For Special Children**, Hastings-on-Hudson, NY 10706

Circle # 194

THE MULTISENSORY CURRICULUM™

For children with traumatic head injury, cognitive disabilities and visual or auditory limitations, this curriculum encompasses 30 interactive programs. Colorful graphics, enlarged screen print, and computer sound create a multisensory interface for readers and nonreaders learning vocabulary, sentence making, grammar and math objectives. Users can navigate through the lessons using a Touch Window, single switch, keyboard or mouse.

Creative Learning, Inc., Nevada City, CA 95959-2617

Circle # 195

TALKING SCREEN

This dynamic, voice output communication system is the first color, programmable, pictographic display system featuring graphics, Mayer-Johnson PCS symbols, clip-art, the ability to create or modify symbols and environmental control capabilities. Talking Screen is easy to personalize for the user and also features auditory scanning for low vision users and display options from one to thirty-two symbols per screen.

Words +, Inc., Palmdale, CA 93550

Circle # 196

BEGINNING ASL VIDEOCOURSE

This award-winning videocassette collection features the Bravo family—a deaf father, hearing mother and two deaf children. Each video focuses on a different set of vocabulary associated with such topics as doctors' visits, shopping, banking, school and getting a job. Each video includes notes on deaf culture and ASL grammar. Recommended for joint viewing and learning by parents and their children.

Sign Enhancers, Salem, OR 97304

Circle # 197

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284, V/TDD or (301) 587-1967, FAX.

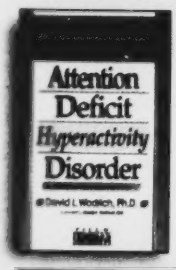
389

EXCEPTIONAL PARENT *Library*

PARENTING YOUR CHILD WITH A DISABILITY

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER



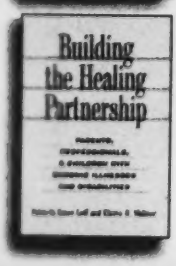
ATTENTION DEFICIT HYPERACTIVITY DISORDER: ***What Every Parent Wants to Know***
D. WODRICH
Prepares parents for at home and at school, empowers and reaffirms parents of their role.
PB070AD **$19.95**

AUTISM

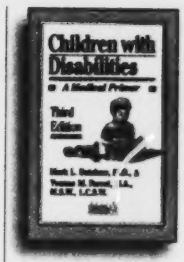
REACHING THE AUTISTIC CHILD
MARTIN KOZLOFF
Focuses on a parent training program that shows how to improve the environment of the autistic child.
BL0630D **$14.95**

DISABILITY, GENERAL

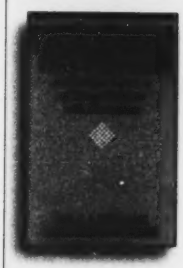
BROTHERS AND SISTERS
A Special Part of Exceptional Families
THOMAS H. PEWELL
Includes 30 parental strategies and 20 sibling strategies suggested by a panel of siblings.
PB072OD **$23.00**



BUILDING THE HEALING PARTNERSHIP: ***Parents, Professionals & Children with Chronic Illnesses and Disabilities***
PATRICIA T. LEFF
BL0570D **cloth: $34.95**
paperback: $24.95



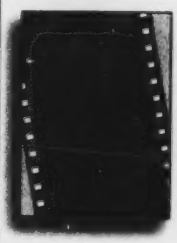
CHILDREN WITH DISABILITIES: ***A Medical Primer***
M. BATSHAW
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.
PB071OD **$29.00**



DECIPHERING THE SYSTEM: ***A Guide for Families of Young Children with Disabilities***
PAULA J. BECKMAN
Informs parents of children (0–5) of their rights.
BL058OD **$21.95**

DISABLED, FEMALE, AND PROUD! ***Stories of Ten Women with Disabilities***
HARILYN ROUSSO
Offers young women with disabilities empowering role models.
GW003EP **$12.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services.***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**



THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals
EP001EP **$14.95**

LIVING IN A STATE OF STUCK: ***How Adaptive Technologies Affect the Lives of People with Disabilities***
MARCIA J. SCHERER
BL064OD **$32.95**

MAKING CHANGES: ***Family Voices on Living with Disabilities***
JAN A. SPIEGLE
Shares self-reports and visions on how families and professionals make changes.
BL061OD **$19.95**

MOOSE: ***A Very Special Person***
W. SCOTT MACDONALD
Moose teaches us that each of us is different and that we have our own unique capacity for loving, sharing, enjoying and learning.
BL065OD **$10.95**

PERSPECTIVES ON A PARENT MOVEMENT: ***The Revolt of Parents of Children with Intellectual Limitations***
ROSEMARY DYBWAD
Captures the author's truly innovative wisdom and pioneering work.
BL059OD **$17.95**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

PLANNING FOR THE FUTURE: ***Providing a Meaningful Life for a Child with a Disability after Your Death***
MARK RUSSELL
AP024OD **$24.95**

THIRD PARTY BILLING FOR SPECIAL EDUCATION: ***Panacea or Mirage?***
JOY J. ROGERS
The use of third party billing to cope with escalating special education costs, especially those not directly educational.
BL066OD **$27.95**

WORKING TOGETHER: ***Workplace Culture, Supported Employment and Persons with Disabilities***
DAVID HAGNER
Assisting individuals to achieve meaningful careers.
BL060OD **$24.95**

DISABILITY, PHYSICAL

COPING WITH CEREBRAL PALSY: ***Answers to Questions Parents Often Ask***
JAY SCHLIECHKOM
Provides answers to more than 300 questions that have been carefully researched.
PE037PD **$24.00**

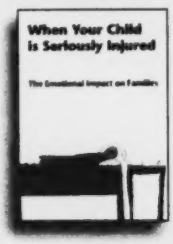
NO TIME FOR JELLO ***One Family's Experience with the Doman-Delacato Patterning Program.***
BERNEEN BRATT
One family's experience with patterning for a child with Cerebral Palsy.
BL062CP **$17.95**

TAKING CHARGE: ***Teenagers Talk About Life & Physical Disabilities***
EDITED BY K.H. KRIEGSMAN
Explore the wide range of issues that teenagers with physical disabilities face as they approach adulthood.
WB013PD **$14.95**

INJURY

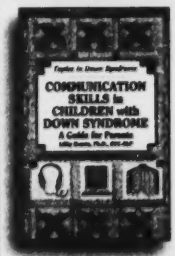
INJURED MIND, SHATTERED DREAMS: ***Brian's Survival from a Severe Head Injury***
JANET MILLER RIFE
Recovery and victory a family can achieve through caring.
BL067OD **$17.95**

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$5.00**



WHEN YOUR CHILD IS SERIOUSLY INJURED: ***The Emotional Impact on Families***
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$2.00**

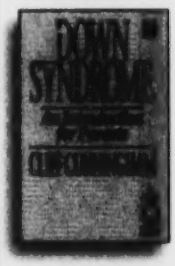
MENTAL RETARDATION



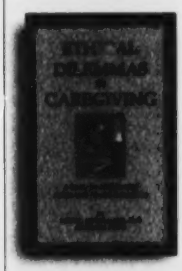
COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME ***A Guide for Parents***
LIBBY KUMIN
Parents learn how communication skills progress from infancy through the early teenage years.
WB031DS **$14.95**

COUNT US IN ***Growing Up with Down Syndrome***
J. KINGSLEY & M. LEVITZ
The authors share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship.
HB073DS **$9.95**

DEATH AND DYING: ***A Guide to Serving Adults with Mental Retardation***
M. HOWELL
Explores psychological, medical, spiritual and legal matters.
GW004EP **$7.95**



DOWN SYNDROME: ***An Introduction***
CLIFF CUNNINGHAM
A comprehensive and well organized work for parents of babies and children. Answers to countless questions.
BL068DS **$12.95**



ETHICAL DILEMMAS IN CAREGIVING: ***A Guide for Staff Serving Adults with Mental Retardation***
M. HOWELL
Examines cases where there are clear-cut dilemmas about the "best" course of action.
GW069MR **$8.95**

SERVING THE UNDERSERVED: ***A Handbook for Caregivers***
EDITED BY D. GAVIN
All the areas of experience affecting the lives of adults who are mentally retarded and old.
GW011MR **$29.95**

Mail to: **Exceptional Parent**, Dept. EP9405, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my:

❑ Visa ❑ Mastercard Exp. Date ____/____ Signature _____

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

CHILDREN'S PAGE

MY BROTHER

by Carlo Testa-Aviles

Hello. My name is Carlo. I have a brother named James. I am lucky to have him as a brother because I know what it's like having a brother with a disability.

My brother is four years old. He attends school at Meadowwood—it is a good school. I attend school at Caravel and I like it a lot. James started walking at the age of two and a half. He is working on talking.

My brother likes *Kidsongs* movies and books. My brother likes to eat; he will eat any piece of food you give to him, ha, ha, ha. When people call my brother retarded I don't care, nor do I listen to them. I don't believe that there is any label that can be put on my brother or anyone else's. We are all alike in this world, and we are all different, too. I love my brother James.

Carlo and James live in Hockessin, Delaware, with their parents Bob and Donna Aviles and their new little sister, Estella Grace. Carlo is a fourth grader at Caravel Academy in Bear, Delaware. James, who has Coffin-Lowry syndrome, now attends kindergarten at Forest Oak Elementary School in Newark, Delaware. Both boys enjoy basketball, baseball and wrestling.

392

PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

Full Range of Accessories

A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.

Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.
All Convaid buggies feature our patented folding design which eliminates slump and the hazard of accidental folding. Imagine the possibilities.
Made in the USA. Five Year Warranty
Call today for your free
the location of your nearest dealer
1-800-552-1020
Convaid
PRODUCTS INC
P.O. Box 2458 • Palos Verdes, CA 90274 USA
(800) 552-1022 • (310) 539-6814 in CA
Fax: (310) 539-3670

Circle #16

Tri-Angles

Three angles, three times the therapy - the new TriStander® 58 positioning stander from Tumble Forms®.

Like the original TriStander 45, the new TriStander 58 is actually three standers in one. A unique design allows infinite adjustments between vertical, prone and supine so you need only to invest in one stander to meet all of your positioning needs. The frame is adjustable for height and what's more, the module support components come in a variety of sizes and çan be ordered separately allowing you to adapt the stander to your client's individual size and shape. The new TriStander 58 accommodates individuals from 45 to 58 inches tall; TriStander 45 accommodates those 32 to 45 inches.

Three angles, one stander, unlimited use. For more information call 1-800-631-7277. In Canada, call 1-800-665-9200.

Tumble Forms® tristander® 58
by **Preston.**

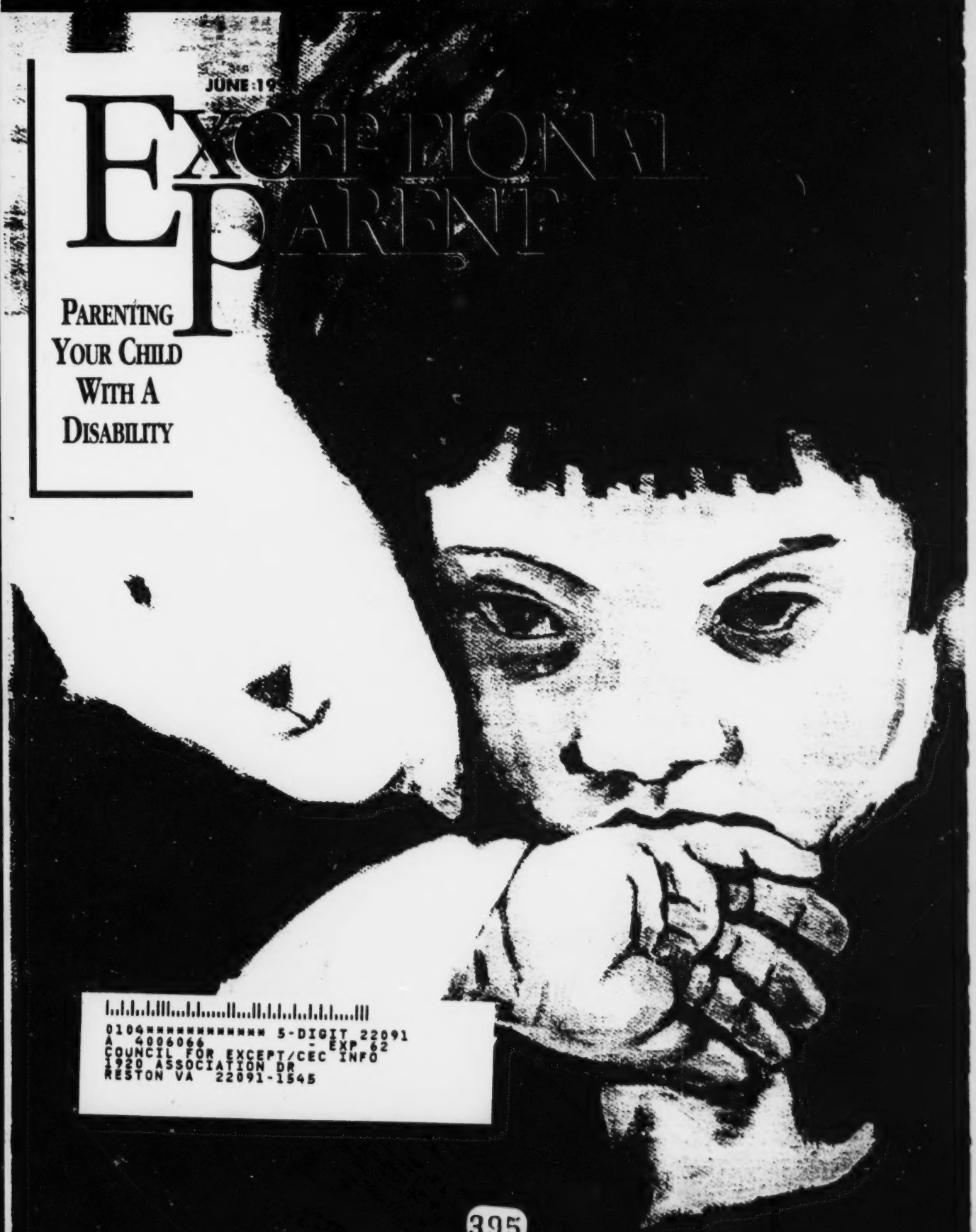
Circle #7

SPECIAL TELECOMMUNICATIONS ISSUE

JUNE 19

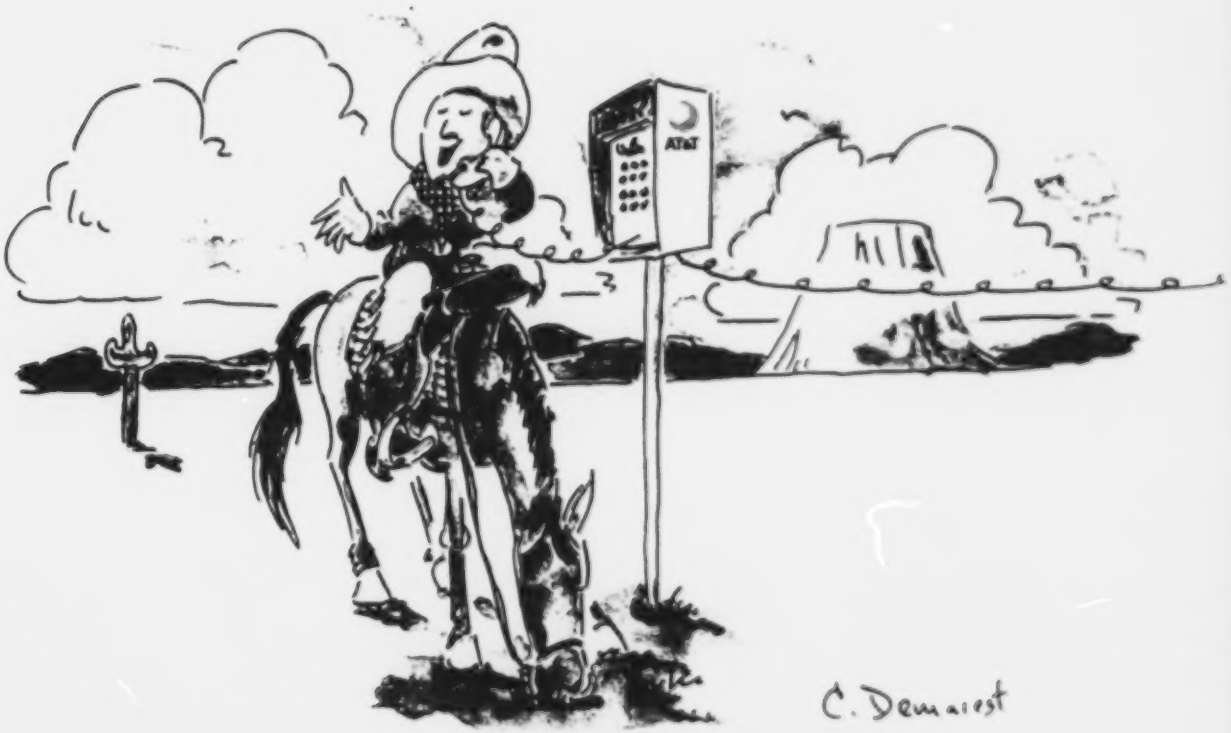
EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY



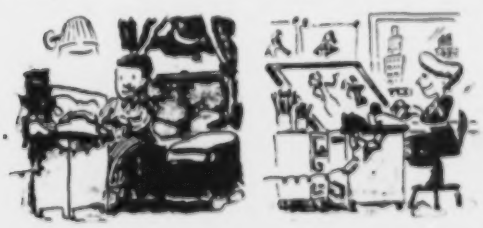
0104NNNNNNNNNNNNN 5-DIGIT 22091
A 4006066 - EXP 62
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1545

How easy is it to call anyone with AT&T Long Distance Relay Service?



This easy: 1 800 855-2880 (TT/TTY)

Anytime. Anywhere. Anyone. One easy number is all you need to place long distance relay calls from any state...to any other state...day or night...to anybody who's near a phone. And relay savings are easy too. With AT&T **True USA**℠ Savings, you qualify for discounts when you spend as little as $10 a month on AT&T Long Distance Relay calls.* At AT&T, we're dedicated to making phone calls easy for anyone. Anytime. Anywhere.



1 800 855-2881 (Voice) • 1 800 855-2882 (ASCII) • 1 800 855-2883 (Telebraille)

*For more information or enrollment, call 1 800 855-5232 (TT TTY)

AT&T

396

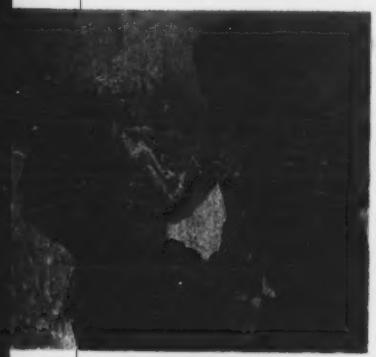
Proud Sponsor of the World Games for the Deaf

Circle # 2

EXCEPTIONAL PARENT

JUNE 1994
VOL. 24, ISSUE 6

PARENTING YOUR CHILD WITH A DISABILITY



COVER:
Four-year-old Katie White—as painted by mom, Michelle—cuddles her bunny. More of Michelle White's artwork appears in this issue, beginning on page 22.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only); All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

FEATURES

Kate's Song by Michelle White 22
Katie's mother celebrates her daughter's life through art.

Parents Online 27
Parents share their experiences with telecommunications.

Getting Started with Telecommunications by Peter Green 30
Everything you need to know before you sign on

Cruising the Internet by Bill McGarry 39
Finding information and support on the "information superhighway"

Disability-Related Electronic Bulletin Boards 43

Empowering People with Disabilities and Their Families by Carol Rasco 47
A parent and policy-maker discusses health care reform.

Augmentative and Alternative Communication Devices 51

Informational Forum: Networking 55

DEPARTMENTS

Editor's Desk 2

Search & Respond 4

Letters 12

Familiar Faces 16

Role Models: CARRIE MILLER 18
Harvard student-athlete talks about growing up deaf.

Fathers' Voices: WHAT'S A TOUGH GUY TO DO? by Thomas P. Nolan 45
What does a tough guy do when there is nothing or no one to fight?

Directory of Advertisers 58

What's Happening 63

New Products 65

Exceptional Parent Library 66

Children's Page:
REMEMBERING DANIEL by Nathan Reiff 68
Nathan remembers a brother and a friend.

PAGE 68

EDITOR'S DESK

At the end of April, I joined more than 1,100 parents in Asheville, North Carolina for the International Parent-to-Parent Conference. Entitled "Weaving the Future From the Fabric of our Past," this meeting was an exciting opportunity to experience the energy and passion of many fantastic, activist parents from all over the United States and other countries. It was wonderful to witness this tremendous display of "parent power," and to be in the company of such a large group of people who are so dedicated to making life better for all children and their families. The next International Parent-to-Parent Conference will be in Albuquerque, New Mexico, March 29–April 1, 1996; save those dates!

STANLEY KLEIN, PH.D.

In May, at the Abilities Expo in Anaheim, California, I had another opportunity to meet parents, families and many of our fine advertisers. During the same weekend, I was able to stop by a meeting of the Fiesta Educativa in Los Angeles to learn about the activities of Hispanic parents and professionals. On the way home, I enjoyed an informative visit to the Utah Parent Center in Salt Lake City.

I look forward to meeting midwestern parents at the Abilities Expo in Chicago in August. All of us at *Exceptional Parent* appreciate the helpful feedback and suggestions—and even the few complaints—we hear from our readers at these meetings.

Words from the White House

In this issue, we are honored to feature an article by Carol Rasco, Domestic Policy Advisor to President Clinton. Having a parent advocate like Mrs. Rasco in the White House is important for all parents. As she reminds us, even though we may lack direct access to the White House, all of us need to continue our individual efforts on health care reform by contacting congressional representatives.

Learning about telecommunications

Thanks to our talented assistant editor, Kim Schive, this issue brings us into the modern age of telecommunications!

To gather information about how parents are using telecommunications, Kim went online and posted a few brief requests for people to share their experiences. The response was incredible! More than 300 parents, professionals, and adults and children with disabilities responded with wonderful examples of how the power of telecommunications has enabled them to meet friends with similar concerns, learn more about helping children and families, even get help with the diagnosis of children who have rare disorders. Kim heard about a variety of ways that parents are using this technology—from weekly, online, support group meetings to online contacts with adults who have disabilities, allowing parents a glimpse into their children's future.

Kim had hoped to respond personally to everyone who shared their stories, however, she also had to get this issue out on time! We both want to extend our deepest appreciation to all those individuals who shared their experiences—your personal stories are reflected in this issue.

I am proud to announce that my personal telecommunications phobia has been cured! In addition to Kim's contribution, I credit my cure to the articles by Peter Green ("Getting Started with Telecommunications") and Bill McGarry ("Cruising the Internet") and most of all, to the beautiful letters—"electronic mail," actually—we received from parents everywhere. I am very excited about the vast potential this technology provides for sharing our compassion and knowledge with each other.

Just after the Abilities Expo in Anaheim, I met with the Worldwide Disabilities Solutions Group at Apple Computer in Cupertino, California to discuss our plans for collaboration between *Exceptional Parent* and Apple's new online service, eWorld (see page 30). Look for more information on these exciting developments in the July issue.

EDITOR IN CHIEF
Stanley D. Klein, Ph.D.
Professor of Psychology,
New England College of Optometry

ASSISTANT EDITOR
Kim Schive

EDITORIAL STAFF
Andrew M. Bissaro
Valerie Steele

EDITORIAL INTERNS
Simone Albeck
Zlati Meyer
Annabel Tan

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING
Terri M. Sutera

VICE PRESIDENT, SALES
Kerry J. Cannon

AD TRAFFIC MANAGER
Stefanie Ferrante

CIRCULATION MANAGER
Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS
R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION
Lawrence Qualiano

FINANCE MANAGER
Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc.
Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription information and advertising information, see page 58.

BPA International Consumer Magazine Membership Applied for August 1993.

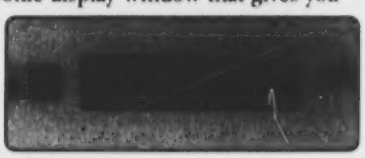
Now DigiVox Gives You Even *More* Value.

Many of you have told us how pleased you are with all the portable power you've found in the DigiVox® augmentative communication aid. In fact, some of you feel it offers such an extraordinary value that you've asked for even *more* of a good thing.

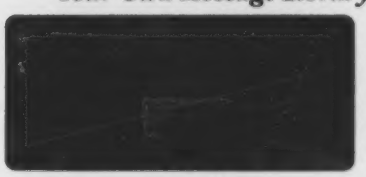
Announcing 8 Full Levels. In response to your requests, we've *doubled* the DigiVox's original 4 memory levels, to give you *8 full levels* with up to 48 addressable message-areas on each. That means you can now provide a user with as many as 384 single-access messages. And if you want, just think what you can do with sequencing.

Superior Sound Quality. DigiVox's advanced digital technology lets you make high-quality recordings and play them back in the clearest, most natural-sounding speech available on a communication aid.

Easier Programming. With DigiVox, you have a built-in electronic display window that gives you step-by-step instructions, and guides you through the programming process. This reduces the need to memorize program codes.



Your Own Message Library. DigiVox gives you all the built-in message time you need (up to 35 minutes, fully extended model). But it doesn't stop there. It also lets you save an *unlimited* number of additional messages, simply by copying them to a floppy disk. And you don't have to buy a computer system to do it - just an inexpensive DigiVox disk drive.



Personal Support. Plus, when you purchase a DigiVox, you get personal training *and* direct access to our experienced Customer Support staff to answer any question you might have.

Unequalled Value. You'll find DigiVox gives you more built-in capabilities and standard accessories (such as overlays, shoulder strap, and 3 access methods) than any other digitized aid. And it's surprisingly affordable, too. So, when you compare feature for feature, we think you'll agree DigiVox is an unequalled communication value.

If you'd like to know more about the DigiVox - or our *rental program* - call us toll-free, at **1-800-344-1778.**

TECHNOLOGY INC.

SEARCH

Feeling "Different"

I am the parent of an eight-year-old daughter with Down syndrome. Her level of retardation is very mild. She is enjoying second grade in an inclusion program in Falls Church, Virginia. This year, however, she has become more aware that she is "different" from the other children and that she learns more slowly. She wants so desperately to be included and accepted.

The children and staff have been very loving, patient and supportive; but, we all are seeing a lot more acting out and inappropriate behavior. We are seeking new approaches to handle discipline in an appropriate manner while helping her to maintain her self-esteem and get in touch with her emotions.

K.M., Virginia

Skeletal Anomalies

Our three-year-old daughter, Amanda, was born with significant skeletal anomalies. Her legs are normal to the knees which she can bend. From each of Amanda's knees extends a three-toed foot with sole turned inward. Three of Amanda's fingers on her right hand are webbed—two will be surgically separated. She also has a heart condition—hypertrophic cardiomyopathy with asymmetric septal hypertrophy—but this has been managed well throughout her life.

We have received many medical opinions about Amanda's legs. Recommendations have included splinting, partial amputation with prosthesis use and other surgeries. We have not yet found an option with which we are comfortable.

Amanda is very bright, busy and inquisitive; her disability has not impeded her development in other areas. We have never seen or heard of any children similar to Amanda, but as we consider medical options and plan her education, we would be grateful for the opportunity to correspond with other families facing similar choices. We would also welcome referrals to resources for additional information.

D.D., Pennsylvania

DiGeorge Syndrome

We are the parents of a three-year-old boy who has DiGeorge syndrome. We would welcome correspondence from other parents of children with this syndrome, as well as professionals or organizations who may have current medical literature on this condition.

T.A. & J.A., Colorado

Teeth Grinding

Our nine-year-old daughter, Nicole, has been diagnosed with pervasive developmental disorder, autism and bi-polar disorder. I sometimes wonder if these diagnoses are correct. Nicole is non-verbal but can answer questions by pointing to word cards with no physical assistance.

I am writing in regard to Nicole's habit of grinding her teeth. This is something she would do off and on in the past; now, she does it constantly. The dentist said that the teeth in her jaw are quite worn. He acts as though there's nothing that can be done. Nicole grinds her teeth so hard at times, I'm afraid they may actually crack. She has several permanent teeth and I don't see how they can last a lifetime under these circumstances. I'd appreciate any helpful suggestions.

A.T., South Carolina

Robinow Syndrome

Our three-year-old son, Zachary, was born with Hirschsprung disease and hydronephrosis of the kidneys. At six days of age, he underwent surgery for an ileostomy and ureterostomies. At two months of age, he began having seizures, now controlled by medication. His pinkie fingers and toes are not fully developed—the nails are just dots. He functions at a three- to six-month-old level. He doesn't have total head control, but can roll all over the house and hold a bottle. He will eat soft baby food but cannot chew.

Because of his physical features—widely spaced eyes, low-set ears, high palate, seizures, short stubby fingers and toes, flattened facial features, micropenis, undescended testes and simian creases—Zach has been diagnosed with Robinow syndrome. We do not know what his future will be like because his doctors have yet to find another child with the same combination of problems as our son.

My husband and I love our son dearly and are hoping to find someone who has a child with similar problems. We would also be glad to receive and share information on caring for an ileostomy and ureterostomies.

J.L., Michigan

Vomiting Problem

Our one-year-old son, Jimmy, was born with meconium aspiration and a grade IV brain hemorrhage. He has cerebral palsy, a seizure disorder, cortical blindness, temperature instability, diabetes insipidus and a poor suck/gag reflex, for which he is fed exclusively through a G-button.

At six weeks of age, before Jimmy was released from the hospital, surgery was done to insert a gastrostomy feeding tube and to perform a Nissen procedure to prevent reflux. At three months of age, the G-tube was replaced by a Bard G-button. Around this time, Jimmy began vomiting following some of his feeds. We tried to find a pattern for these episodes, but they seemed to occur randomly. Since this time, the amount of formula we have been able to give Jimmy without provoking vomiting has decreased from six to two ounces

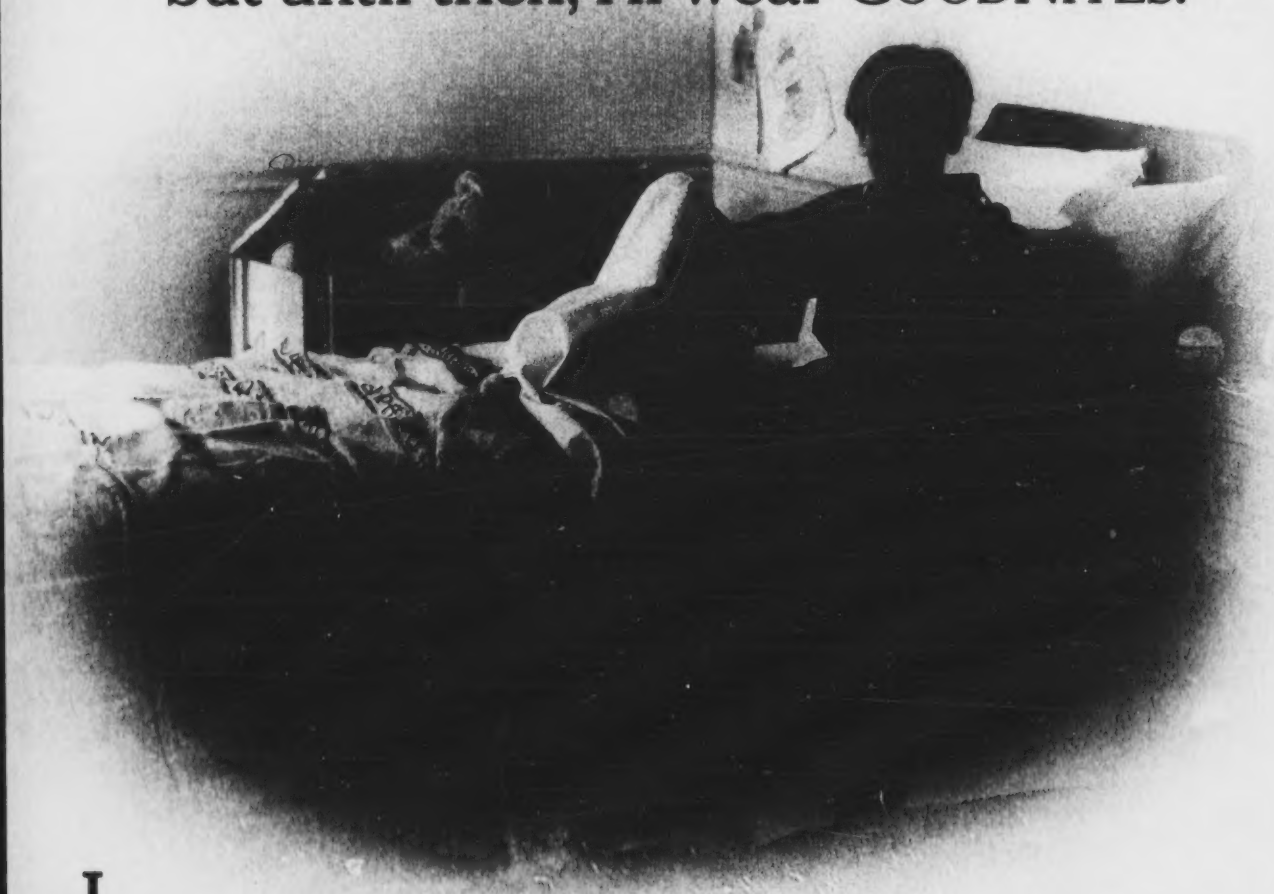
Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard Street, Suite 308
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

"Bedwetting is something I'll outgrow, but until then, I'll wear GOODNITES.™"



Introducing new PULL-UPS® GOODNITES™ Absorbent Underpants for older children—45 pounds and up. Your child slips them on at bedtime and—accident or not—wakes up to dry sheets, dry pajamas. And a whole new positive attitude.

Even with the super-absorbent lining, GOODNITES™ Absorbent Underpants are so trim, they disappear under pajamas. Nobody needs to know your child is wearing them. And with no sheets to wash, mornings are hassle free. Everyone starts the day right.

We developed GOODNITES™ with the help of pediatricians and other childhood experts. We've put all we learned about bedwetting in a book. For your free copy, send $1.00 postage and handling to GOODNITES™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

40

Circle # 147

per feed. Consequently, he has had trouble gaining weight, even though we try to feed him every couple hours using a high-calorie, concentrated formula.

We have tried a variety of anti-reflux and stomach medicines—including Zantac, Bethanecol, Cisipride and Reglan—without much success. Upper gastrointestinal and milk scans show some reflux. A pH probe test will be done soon. Additional surgery on his Nissin is also a possibility.

We would like to know if anyone has encountered similar feeding problems under these circumstances.

J.K. & T.K., Virginia

Panic Attacks?

Our six-year-old son, Davis, has Coffin-Lowry syndrome. Cognitively, he is at a two-year-old level. He had sensory defensiveness as an infant, but has overcome much of that. Due to scoliosis, he has an awkward gait and poor coordination, but he gets around just fine.

At age four, he had three bad falls during a two-week period. He became afraid of walking, started falling for no apparent reason and, eventually, stopped walking unaided entirely. That lasted for about three months.

The same thing has happened twice since then, each time about a year apart.

"The Rain-Pretty Church," by Alex Blum

He has what looks like a seizure—his body goes rigid and pulls into a fetal position with his head thrown back. His normal self-protection mechanisms fail, and he falls—always landing on the right side of his forehead. He appears terrified. Between episodes, he will have months of normal physical activity.

We have not been able to find a physiological cause for the behavior. Seizures have been ruled out and these episodes appear unrelated to his syndrome. His neurologist thinks he has an abnormally high level of background anxiety that manifests itself in "panic attacks" when he becomes overloaded with unpredictable sensory input. Currently, we are experimenting with a medication.

I am interested in corresponding with anyone who is familiar with this problem, knows its cause or has had success with medications or behavior modification techniques to overcome a similar problem. The neurologist is interested in whether sensory defensiveness in infancy may be related to higher anxiety levels, panic attacks and compulsive behavior in older children and adults.

M.I., Washington

Ring Chromosome 22

We are the proud parents of a 12-year-old boy who was diagnosed with ring chromosome 22 at age five. We have been unable to find much information about this disorder and would like to be in touch with other families and/or professionals who have experience with this syndrome.

T.W. & D.D.W., Washington

Scoliosis

My 13-year-old daughter was born at 27 weeks weighing two pounds, eleven ounces. She suffered a brain hemorrhage and was diagnosed with bronchopulmonary dysplasia, a seizure disorder, profound physical and mental retardation and spastic quadriplegia. A few years ago, she was also diagnosed with scoliosis. Now, the doctor has said she needs immediate surgery, because the scoliosis has progressed to more than 50 percent.

I would like to hear from any parent with a child who has had scoliosis and/or surgery for this condition. I would also like to hear from any parent who has a 13-year-old with disabilities similar to my daughter's—how do you handle everyday things like feeding, clothing, toys, school, social events and the fear that your child will become too big for you to care for properly? I know I am asking a lot, but I need some help and advice to deal with the upcoming years.

D.R., New York

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich

ORTHOPAEDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America.
Steel frame. Duel caliper, drum and coaster brakes available.
Parking brakes standard.
Latest styling and wide choice of colour combinations.
More than 30 specially designed accessories to meet every need.

Circle # 36

402

Berkshire Meadows

is a private, non-profit year-round residential school for children who are developmentally delayed and multiply disabled.

Nestled in the serene beauty of the Berkshire Hills, Berkshire Meadows' carefully designed 15-acre campus houses attractive, homelike residences, extensive physical therapy facilities (including a therapy pool, a Hubbard Tank, and vestibular stimulation equipment) and a cheerful Learning Center equipped with state-of-the-art teaching aids. Here the children are taught techniques to help them to compensate for their tremendous difficulties, and where their bodies are gently persuaded to move more freely and with greater control.

At every stage of the Learning Center curriculum and throughout the rest of the Berkshire Meadows programs we work with each young person to improve his or her ability to communicate. For most of these young people, there has been no incentive to communicate: their basic needs have been provided for, in one way or another, and they have in any event been unable to express needs or wants in ways that other people understand. So the first task is to motivate communication, which we do by offering choices - of toy, snack, drink, etc. By using pleasurable choices and consequences, we provide even greater incentive to the child to break through his or her passivity.

Total and Augmentative Communication

In general, the staff use Total Communication with all our students – that is, we use a combination of sign language, facial expressions and words. However, for many of our students, using normal sign language is not feasible, so we develop individual augmentative communication skills. We teach the use of mechanisms such as object displays, switch-operated scanning devices and VOCAs (voice output communication aids) ranging from simple, pre-programmed devices to sophisticated computers with speech synthesizers. Once a system of communication has been established, we ensure that family members and all staff are trained to understand it, so that the student is spared the repeated frustration of not being understood.

Concomitant with learning to communicate is the ability to impact one's own life. For the youngsters at Berkshire Meadows, this is a primary step toward psychological development and emotional wellbeing.

For more information, please contact: Mrs. Gail Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523)

RESPOND

Transporting Two Non-Ambulatory Children

D.H. (February 1994) has three boys, two of which have multiple disabilities and are non-ambulatory. She was looking for a portable, adjustable means of transporting both boys simultaneously.

Soon after we found out that we were expecting another child, we realized that it would be impossible for one person to transport a 20-month-old child with cerebral palsy and a newborn. Nobody seemed able to offer assistance on this particular problem.

While there are many double strollers available, none are designed to accommodate a child with even a minor disability. Our solution was to take a conventional double stroller and modify it (see photo) so that it could provide the support our 20-month-old child required, and also transport our new baby.

We started with a *Grayco* double stroller and *Fisher Price* bicycle seat.

The stroller was not quite large enough to allow the bike seat to slip into it, so we sawed off the front bumper bar and extended it with a custom-bent piece of electrical conduit. This allowed the bike seat to be placed in the stroller.

The bike seat also required modifications. First, there were side rails that needed to be removed to allow the seat to slide easily in and out of the stroller. Second, we needed a way to secure Alexander's feet. We attached straps to wooden blocks that were screwed into the bike seat's plastic foot protectors. The third modification was a bit more involved. Alexander's lack of complete head control meant that he would need a padded head support. To accomplish this, we heated and bent a piece of one-quarter-inch-thick Plexiglas, bolted it to the bike seat, padded it and covered it with fabric. Last, we added a strap to secure the bike seat in the stroller. The stroller folds down with the bike seat inside so it is easy to handle and fits in an ordinary car trunk.

These modifications were not as difficult and extensive as they sound—the difficult part was figuring out how to make the changes, not actually making them. Alexander is now 30 months old and Amy is 10 months. Additional modifications to the bike seat have been required to accommodate Alexander's growth. Soon, we will have to figure out how to accommodate the growth of both children, so we would welcome ideas. One ready-made product that holds some promise is the Runabout™ (Runabout/USA, Inc., 8025 S.W. 185th, Aloha, OR 97007, 503/649-7922). Runabout "Baby Karts" are fully adjustable, can accommodate from one to three children and also use bicycle seats. However, the Runabout is more difficult to handle and transport than a stroller and carries a higher price also.

D.S., Wisconsin

Celiac Sprue

S.L.W. (March 1994) wanted to correspond with other parents of children who have celiac sprue, a digestive condition which prevents the digestion of gluten-containing products.

My son, now 23 years old, has been on a gluten-free diet since he was 11 months old. He was diagnosed with celiac sprue after suffering from symptoms for five months. After a few days on the diet, his diarrhea stopped.

Here are three sources of more information than you'll know what to do with:

- Celiac Sprue Assn.–USA, P.O. Box 31700, Omaha, NE 68131-0700.
- ENER-G Foods Inc., P.O. Box 84487, Seattle, WA 98124-5787. (Mail order food products. Sometimes you can find the brand "ENER-G" in large health food stores.)
- Gluten Intolerance Group, P.O. Box 23053, Seattle, WA 98102-0353.

Don't forget to always read labels. Also, write to food companies and ask for a list of their gluten-free products.

L.R.H., New York

School Districts With Full Inclusion in New England

J.H. (March 1994) was planning a move to New England and wanted assistance in finding inclusive school districts.

Each state has a Planning Council on Developmental Disabilities. These Councils are an excellent source of information on inclusion and many other topics. You may contact the Planning Council in your state and ask for information about various New England states, or you may contact those states' Councils directly. The numbers would be available through directory assistance; a state's Planning Council is usually in the state capital and/or the largest city.

K.R., Illinois

Lennox-Gastaut Syndrome

D.S. & J.S. (March 1994) have a 22-month-old son who has seizures and autistic symptoms; doctors say he has Lennox-Gastaut syndrome. "We are searching for parents of a similar child," they wrote, "or anyone with a suggestion as to how I could simply get my beautiful son to look into my eyes. It is hard not knowing how to get through to him."

You are practically describing my little girl! Amy seemed perfectly normal for her first two years, then her pediatrician began to wonder why she wasn't speaking as she should. She was a happy child, just rather aloof. At three years of age she received her first diagnosis—mild cerebral palsy—because the neurologist didn't know what was wrong!

Last year, after five frustrating years of neurological testing, she received what we believe is a correct diagnosis of epilepsy. She is now on a combination of drugs that we hope will control her seizures. She has been diagnosed with Lennox-Gastaut syndrome.

Amy remains unable to perform even basic functional living skills. Her teeth are almost flat from grinding in her sleep and constant chewing. She mostly avoids eye contact. She is only partially verbal, does not communicate any desires and is extremely hyperactive.

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34F1

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34F1

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right, Exceptional Parent magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

See reverse side for subscription details

RESPOND

Now, to give you something encouraging after all that! Amy has always been aloof, but loves attention when it's forced on her. Love and hug and tickle your child as much as possible, even if he doesn't seem to understand. Treat him as if you don't notice that he's squirming and trying to avoid you. We have always tried to treat Amy as normally as possible, even when she's literally kicking us in the head! Her aloofness is just a part of her and we try to ignore it as much as possible.

At times it's extremely difficult to love this child, but the dividends, when she loves back, are tremendous. Every night I put her to bed and say to her "Amy, Mama loves you. Can you say 'I love Mommy?'" Only once in nine years did she respond "I love..." but that one time has kept me going for many years. She never tries to kiss or hug me, but she can't stand to have me out of her sight—I take this as her way of saying, "I love you Mommy and never want you to leave me." I may be deluding myself, but it's *my* delusion and I need it!

Actually, she loves on her daddy more than anyone else. She will hug his neck and offer her forehead for a kiss. She will sit on his lap for a moment and say "good morning" to him. Of course, he loves all this attention and is proud to have it directed only at him! But it has taken years to get to this point.

My best advice is just to love your son with all your heart and keep giving him affection no matter what. Hold his chin and make him look into your eyes—even if it's only for five seconds a day. We have been doing this with Amy all along; each year it seems to get easier for her to reciprocate. Her love of her family is obvious, even if it's disjointed.

My only other advice is to find the best neurologist you can. If you don't feel completely comfortable with the one you have, or if you question his commitment to your son's care, find another one. I've been through four of them and only now have one who's willing to pay attention and try the things I feel will be most helpful. Also, do your homework and find out all you can about each thing they tell you, no matter how discouraging it may be. Your son can't speak for himself. He's depending on you to make sure the doctors are doing right by him. They're only human too!

M.E., Texas

□ I know what you are feeling—"Look at me. Please just look at me! I love you more than I could ever say." As I write this, I can hear my sons upstairs babbling together. They are both so beautiful, so special and so different. Our older son has blonde hair and autism; our younger son has brown hair and an attitude. They have their own ways of relating to each other that are fun to watch and hear.

The best advice I can give you is to look for other ways to know that your child is "connecting." My son sometimes looks directly at me, sometimes looks out of the corner of his eye and sometimes looks just over my head toward my hair. I know my son senses things differently than everyone else. He is sensitive to different food textures and noises. He won't wear overalls because of the straps on his shoulders.

Try to find ways to tell when your child is paying attention to you. It's not easy, but there may be some. It's hard to tell what's being taken in by someone who has no way of telling you. We have a wonderful speech therapist who has helped us find other ways for our son to communicate. We tried sign language, but that didn't seem to help. We use lots of pictures, and our son has a touch talker with pictures on it. He can point to a picture of juice, and the box says "I want juice." It's hard for us to think that our son may never talk, but we feel great knowing that we have given him other ways to communicate.

All behavior is communication. When my son is whining and driving me up a wall, as any kid can, I look at what's going on around him. We feel lucky that he communicates his needs so well—if he wants to go outside, he whines near the back door; comes to us, grabs our hands and takes us to the back door; or brings us his coat. He doesn't always look at us or talk, but he does communicate. (I know, it doesn't take away the hurt, does it?)

I don't want to give you some quick psychology lesson or sound as though I've fully accepted everything with my son—I just know what you're going through and want to help you change your expectations.

K.S., Illinois

Vocal Assistant™

The Vocal Assistant provides hand-held basic speech at a very affordable price.

The Vocal Assistant is a digital record and playback communication device. Record 16 messages (any voice, any language) in just minutes. Each message is available for playback with the touch of a key.

A paper overlay slides into the water resistant keypad so you can use pictures or words to illustrate the message stored in each key.

Features

- 16-message keypad with overlay pocket
- Built-in microphone and speaker
- Lightweight and compact
- Automatically conserves battery power between uses
- Records messages in any order
- Remembers messages during battery replacement
- Uses a standard 9 volt alkaline or rechargeable battery

gmr labs

1030 E. El Camino Real #308
Sunnyvale, CA 94087

Phone 408 · 985 · 7200
Fax 408 · 243 · 3731

Circle # 34

LETTERS

Laughter Helps!

Reading what other parents write about their everyday life really helps me cope. That is why I really enjoyed the April 1994 issue which featured quite a few articles from parents. I especially enjoyed the feature *Sense of Humor Required.* I laughed while I was reading!

This article reminded me of some of my own experiences that were not so funny when they happened, but seem humorous now—like the day my six-year-old daughter, who has autism, went to the park with her father to see the ducks. A short time later, they came home… soaking wet and muddy from head to toe. She had jumped right into the lake, and Dad had jumped in after her. I was horrified at the time, but now, remembering her sheepish expression makes me laugh. Maybe you could start a regular column where parents could write about some of their funny experiences.

P.C., New York

EDITOR'S NOTE: Great idea! We enjoyed your story and would love to hear from others.

If you could peek in my mailbox…

I know you know how you enhance the lives of those with special needs with every issue. Still, you would be amazed if you could peek in my mailbox, or listen in on my recent phone calls. Since you mentioned *The Myelin Messenger* newsletter (for families with children with insufficient myelin, c/o Ruth Anderson, HC-29, Box 686, Stable Lane, Prescott, AZ 86301-7435), parents have been calling and writing daily. They are so grateful to *Exceptional Parent* for printing information that allowed them finally to connect with other parents who are dealing with this rare disorder. Several have called with tears of joy because they are so glad to find out they are no longer alone.

For two families, that happened to be the first issue of *Exceptional Parent* they had ever seen. They saw it in a doctor's office, and were so grateful they had picked it up. Two other families each had two children with this disorder, but had never made contact with other, similar families. Another two parents who wrote were physicians who themselves had children with this disorder.

I have heard from many other families—in Alaska, Nova Scotia, Florida, California and *everywhere* in between. I have had a firsthand look at the phenomenal, positive impact *Exceptional Parent* magazine is making on families; we are all very thankful!

R.A., Arizona

Viewpoints on Inclusion

I am writing in response to Dr. Edwin Martin's guest editorial, *Inclusion: Rhetoric and Reality* (April 1994). As our parent group struggles to implement inclusive practices in our school district, it is a shock to have Dr. Martin stating that "the prospects for inclusion are not encouraging." Why would any parent want to give up a child's birthright to belong? Sure, inclusion involves risk, but we are enjoying educational benefits for our children today that were earned by parents who took risks in the past. Now, it is our turn to make a difference for the children of today and tomorrow.

The studies that Dr. Martin cites involved students who did not have an opportunity for an "inclusive" educa-

EXCEPTIONAL PARENT

- ***To reach out to parents of children with disabilities and special health care needs.***
- ***To empower mothers and fathers by providing practical information and emotional support.***

EDITORIAL ADVISORY BOARD

LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING
PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford and Lincoln-Mercury Divisions

Circle # 30

The Next Step In Dealing With Incontinence.

High density fibers wick fluid from surface quickly.
"Cells" trap liquid in the center.
Reinforcing fibers prevent pooling, maximize comfort.
Center reservoir holds fluid from surface.
Fibers bundled in cells to transmit fluid to center and spread it throughout the garment.

The chart above shows how Hypersorb™ works. The photo shows how good it looks doing it. A new level of efficiency, a new level of fashion.

Reusable and guaranteed for one year (details available), in girls, women, boys and mens models, it's what's next. For orders or a catalog, just call.

Girl's Model

TMI

TECHNOMARKETING INC

307 Bacon Road • Rougemont North Carolina 27572

(919) 477-1387 • Fax (919) 477-2294

©1994, TMI. Hypersorb Patent Pending.

Circle # 122

For people with disabilities,

WE CAN

turn your computer into an open door.

A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3383 (TDD); in Canada, 1-800-465-7999.

At IBM, we can do more than you think.

IBM INDEPENDENCE SERIES

© IBM Corp. 1994. ® IBM and Independence Series are registered trademarks of International Business Machines Corporation.

Circle # 121

tion for the majority of their school years. Furthermore, in addition to academic performance, researchers should focus on the social and emotional needs, and personal and collective citizenship responsibilities of our children. Some benefits of inclusion—a first birthday party invitation or a teenager's first non-disabled friend from school—are difficult to translate into hard data.

Studies are helpful, but most of us cannot wait. We are moving forward with inclusion using parental support groups, collaborative school partnerships focused on "best practices" and remaining ever alert to what our children "tell" us.

P.A.D., Pennsylvania

☐ As a parent of an 18-month-old who has Down syndrome, the title of Dr. Martin's guest editorial intrigued me. I was disappointed. Martin writes, "Neither parents nor professionals should accept rhetoric in the place of data." He should have followed his own advice.

Martin cites data on the percentage of youth with disabilities failing at least one regular education high school course. These data could be interpreted in many different ways. Advocates of inclusion might say that this reinforces their claim that regular education should be strengthened to meet the needs of students with disabilities. Others might conclude that this points to a failure of mainstreaming. In any case, Martin needs a great deal more data and detail to support his conclusion that "...the data indicate that the prospects for inclusion are not encouraging."

As a history teacher, I can testify to the extraordinary impact of inclusion on the lives and academic performance of my many special education students. Martin is right in calling for long-term studies of "outcomes." But parents like me will not wait for the findings of such studies before they demand what most see as the most empowering education for their children—inclusion.

I am disappointed in *Exceptional Parent* for making this a "guest editorial" without comment or response, thereby giving it the *Exceptional Parent* imprimatur.

J.H., California

☐ I really do not have any interest in knowing how many graduates of a program are employed or in post-secondary programs. This will not tell me anything about the future of *my* child. I am much more interested in how teachers and administrators view children with disabilities. Are they inclusive or exclusive? Do they see my child, or do they see his disability? These are the truly important questions.

Martin attempts to make a case for collecting more data. His article, however, provides a perfect example of how data can be misused. For example, he cites the percentage of youth with disabilities who fail at least one regular education high school course. *But he never provides comparable numbers for students who do not have a disability.* This reminds me of the data once used to "prove" that having a child with a disability led to marital strife and discord—fifty percent of such marriages ended in divorce! What one was never told was that the divorce rate was identical for couples who did not have a child with a disability. Likewise, I suspect that a similar percentage of youth without disabilities fail at least one high school course.

Martin also attempts to correlate segregated education with a higher rate of college attendance by using the example of children who are deaf. But such children may also have a lower rate of cognitive disabilities. That factor could have more to do with their rate of college attendance than the fact that they are more often educated in segregated settings. And what does college attendance have to do with being accepted in the community?

As a parent who has worked hard over the last nine years to include my child in the community, I am willing to say that inclusion is a necessary piece of life's puzzle. I work with many families who don't need data to tell you the difference inclusion has made in their lives. I believe that spending money on evaluating federally-funded demonstration projects is a waste of time. Let's put money into providing the supports needed to make inclusion successful.

Families must be involved in including their children in their community, and school is often the place to begin. My son receives some services outside the regular classroom but is seen by all his classmates as just another kid. Josh plays on local sports teams, participates in the annual talent show and knows more people in our town than me. I believe these things are the true indicators of what Josh's life will be like in the future—not whether or not he attends college.

I agree with Dr. Martin that inclusion practices need to be continually reviewed. I believe that support and training of regular and special educators is the real issue. I look forward to reading more from parents on this subject in future issues.

S.M., West Virginia

DR. MARTIN REPLIES: I appreciate the chance to reply to the thoughtful letters concerning my guest editorial. Each raises concerns about my views, fearing incorrectly, that I oppose "inclusion" in principle. The letters elicit feelings of compassion and support from me—I applaud the hope and dreams of these parents and wish them and their children well.

My goal in writing the editorial was to elicit thought and to caution readers that inclusion, as implemented, will almost certainly be of uneven quality. Almost five million children and hundreds of thousands of teachers will be involved; no broad-scale, tested preparation and teacher training has yet been demonstrated. Past efforts toward education reform, including parts of IDEA (P.L. 94-142), have floundered for these very reasons, leaving parents and professionals frustrated and disillusioned. Testable reform is needed; the support of teachers and funding sources must also be established.

Further, since school systems have not kept careful records of the "outcomes" of students in special education, many problems in the system are only now becoming obvious. The statistics I cited were intended to make that point, to provide guidance for the future.

As a government official, I felt it was a victory that the overwhelming number of children with learning disabilities were receiving at least some of their education in regular classrooms. I did not know, nor did anyone else, that two out of three children were failing one of those classes.

continued on page 53

kid-kart™
cares about kids.

kid-EZ tilt/recline™

made in USA
PATENT PENDING

Proving good looks, convenience and proper positioning work wonderfully together.

kid-EZ. Adjustable High Chair Base

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle # 46

FAMILIAR FACES

*Seven-year-old **Sydney Greer Hinks** enjoys swimming, horses and riding the school bus. Sydney, who has autism and epilepsy, lives in Katy, Texas with her mom, Nancy; dad, Alan and dog, Kanga. Sydney is in first grade at Cimarron Elementary School.*

*Horseback riding is one of six-year-old **Cory Powell's** favorite activities. Cory, pictured here with his dad, Billy, "has lots of experience with horses." Last year, he rode with a group called "Horses Helping Handicapped." Cory, who lives in Port St. Lucie, Florida, has cerebral palsy.*

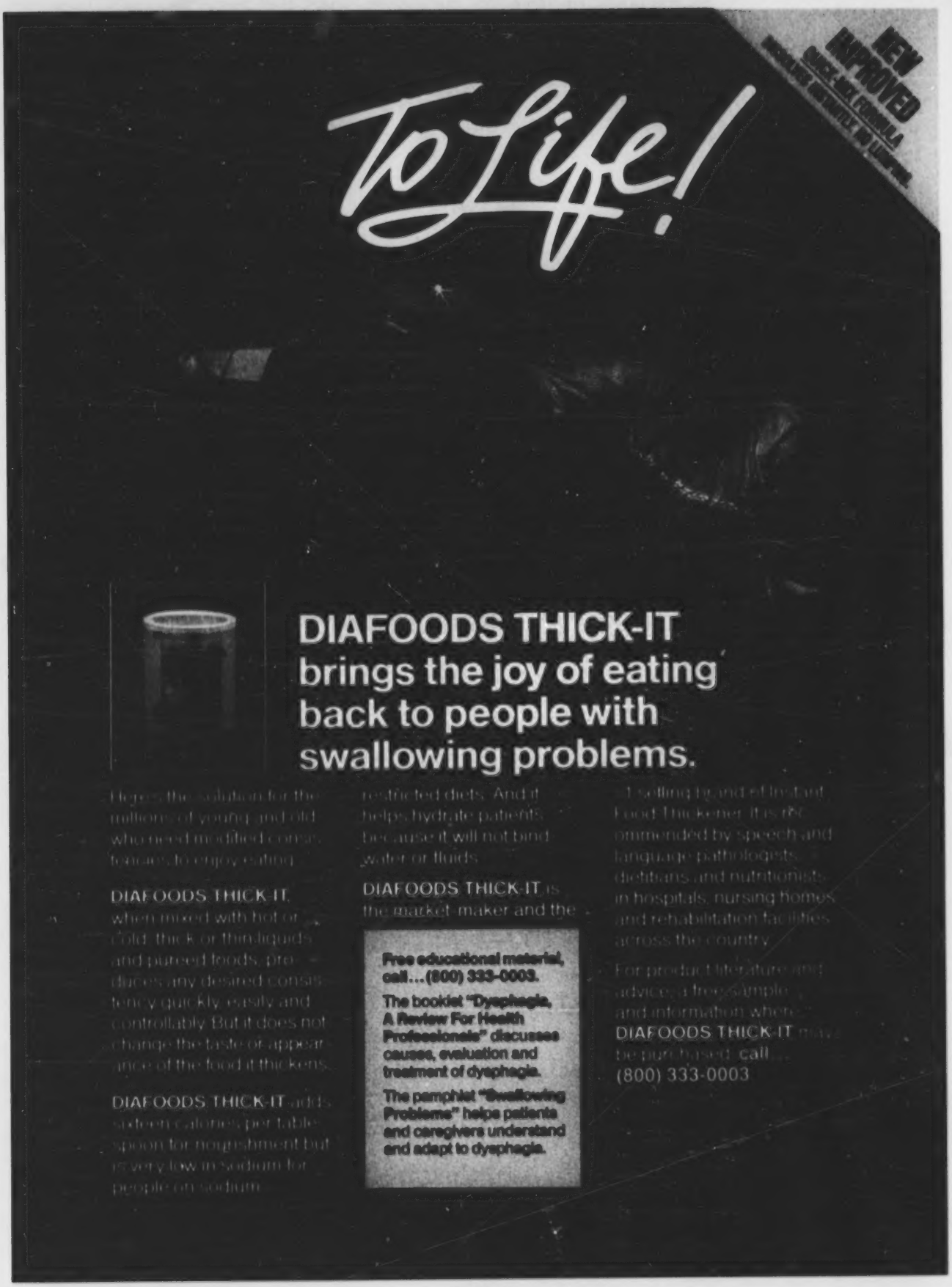
*Chocolate cake is always welcome at the household of **Dakota Josef Rizzo.** Dakota, seen here celebrating his first birthday, is developmentally delayed. In hopes of finding a diagnosis for Dakota, his parents, William and Tracy, published a SEARCH letter in EXCEPTIONAL PARENT last year; they say that although Dakota remains undiagnosed, their SEARCH letter has resulted in many new friends.*

*Two-year-old **Alexandra Sellitti** of Sayville, New York, flashes a charming grin. Alexandra, who was born with myelomeningeocele and hydrocephalus, was recuperating from hip surgery—her seventh operation in two years— when this photo was taken at Easter, 1994. "She remained her usual happy self through the whole thing," says her mother, Rosemary. "She's a real trooper and we are all very proud of her."*

***Ryan Lutak**, 11, of Fords, New Jersey, finds his wheelchair surrounded by classmates from the Matthew Jago School in Sewaren, New York, during a fun-filled field trip to the Statue of Liberty. Front row (from left): Jackie, Heather; back row: Megan, Stephanie, Steven, Louis, Ryan, Daniel and Michael. Ryan has spina bifida.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent?* Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

412



DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market maker and the leading brand of instant food thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call...(800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice on a free sample and information when DIAFOODS THICK-IT may be purchased, call (800) 333-0003

Circle # 169

Carrie Miller

Harvard student-athlete talks about growing up deaf

Carrie Miller, 19, has been deaf since a bout with spinal meningitis at the age of 15 months. Carrie, who has been swimming competitively since the age of nine, is a two-time participant in the World Games for the Deaf. At the 1993 World Games in Bulgaria, she won an unprecedented 10 medals—nine golds and a bronze. Next fall, Carrie will enter her junior year at Harvard University where she is a top swimmer and student, majoring in environmental sciences and public policy. EXCEPTIONAL PARENT *caught up with Carrie in April, during an hour's free time between a meeting with Harvard swim coach Maura Scalise and a marine science seminar.*

Gold medal winners: *Carrie, 14, was a member of the U.S. women's 400-meter free relay team that won a gold medal at the 1989 World Games for the Deaf in New Zealand. Team members included (from left) Celine Lawler, Lauren Abbot (face partially hidden), Jennifer Griffith and Carrie.*

After I recovered from spinal meningitis, my parents did not realize that I was deaf. I wasn't diagnosed until the end of the following summer.

At that time, my father was almost finished with graduate school at the University of Pennsylvania. My parents started looking at schools for the deaf in areas where my dad had job offers. My father accepted a teaching job at the University of Delaware because my parents were impressed with the parent-infant program at the Sterck School, Delaware's state school for the deaf. Sterck's program used the philosophy of "total communication." My parents had looked at, and decided against, schools with strictly oral programs. They wanted me to talk, but they believed that I needed sign language also.

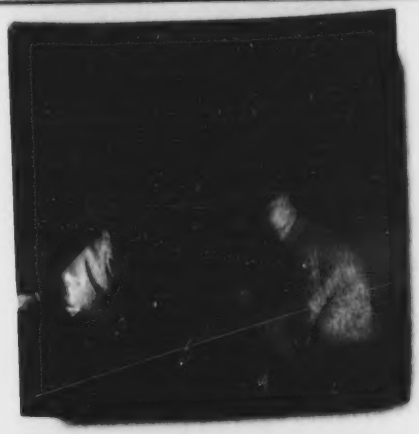
When I started first grade, my parents wanted me to be mainstreamed all day with an interpreter. At the deaf school, I had been put in classes with kids who were three or four years older than me because I was doing so well. My parents wanted me to spend more time with kids my own age; I would also be going to school with a few hearing friends from my neighborhood who knew some sign language—back then, my speech wasn't as intelligible as it is now, so my friends had to know sign language to understand what I was saying.

I think I would have been frustrated by low expectations if I had stayed at the deaf school. I'm sure none of those teachers ever expected me to attend Harvard.

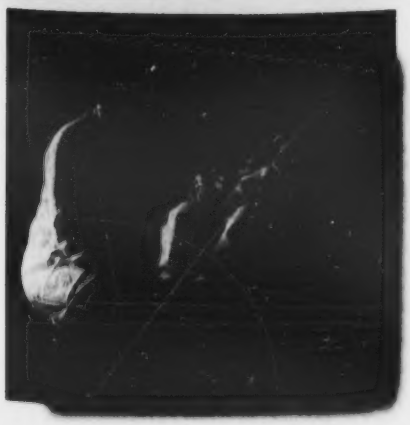
I had already been mainstreamed for half-days in kindergarten and the school for the deaf thought that arrangement should continue. They wanted me to take social studies and English classes at the deaf school. My parents refused to sign the IEP; they even brought a lawyer to the IEP meeting. Finally, the school backed down.

Although I was mainstreamed for all my academic subjects, I still received services from the school for the

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.



AND THEN BACK OUT AGAIN."



At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

P-CAP

CHRYSLER CORPORATION

For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Circle #90

deaf. I would go back to the deaf school for auditory training and speech therapy. In seventh and eighth grade, my parents noticed that I was feeling isolated from my deaf friends. So, they arranged for me to take a few classes at the deaf school—classes that were not educationally important like shop and cooking.

After eighth grade, my father got a job at the US Naval Academy, and we moved to Annapolis, Maryland. One other deaf girl attended my high school there, but she was very oral and her mother did not want her to learn sign language because she thought the girl would lose her ability to speak. Of course, I could sign *and* speak, and while her daughter was struggling to keep up with regular classes, I was in honors classes with an interpreter. When this girl's mother found out that I was doing better than her daughter, she decided to let her daughter learn sign language and get an interpreter. The girl eventually ended up in honors classes with me.

Mainstreaming

In general, I'm happy that I was mainstreamed. A lot of deaf people are surprised that I didn't go to a deaf school. I think I would have been frustrated by low expectations if I had stayed at the deaf school. I'm sure none of those teachers ever expected me to attend Harvard.

On the other hand, I did attend the school for the deaf for some classes, and I had deaf friends while growing up. Especially during early adolescence, the time I spent with other deaf kids helped me to get through that rough period in my life. Even if a deaf child is mainstreamed, I think it is important that deaf people are around at crucial times while he or she is growing up. You need to have the right balance between a child's educational needs, social needs and development of a strong identity.

Communication

When I was young, my parents emphasized using Signing Exact English (SEE), so I would learn English grammar. Once I had a good grasp of the grammar, we stopped signing all the word endings—"-ing," "-ed," "-s" and so forth. In elementary school, a lot of my interpreters would want to use American Sign Language (ASL). But my parents said, "Look, ASL is going to be around for the rest of her life. Right now, we want Carrie to learn English!"

I feel that this approach really did help me learn English. Without already having a good grasp of English grammar, I would not have been able to understand written English as well. My parents also emphasized speech therapy. As a result, I speak pretty well. People can understand me. My speech is not perfect, but I can have conversations with my hearing classmates.

(Above) Carrie, at 18 months, demonstrated an early love of water. (Left) Carrie attended a local elementary school with other children from her neighborhood.

Swimming

I started swimming when I was about seven years old. My house was one block from the neighborhood pool, so I saw a lot of the older kids swimming and decided I wanted to swim too. My first swimming teacher lived in my neighborhood; she also taught at the deaf school and could sign. At first, I just swam during the summer, but I was enjoying it so much that I joined a team at the YMCA when I was about nine. After my family moved to Annapolis, I trained with the Navy Junior Swim Club and the Retrievers Aquatic Club in Baltimore.

My father had an Italian friend whose brother was deaf and had gone to the World Games for the Deaf in 1981. So my father decided to get more information about the Games. In 1985, I was still too young to compete; in 1989, my dad and I decided to go to Florida for the tryouts. And I made the team! The Games were held in New Zealand. I was fourteen years old at the time and beat many of the veteran swimmers. Of course, I was very excited.

In New Zealand, my performance surprised everyone. But in 1993, when I went to the World Games in Bulgaria, everyone knew who I was. I was under a lot of pressure to maintain my reputation. I won nine

golds and one bronze. The bronze came in the fifty-meter freestyle. I could have done better in that race, but because Bulgaria is a very poor country, they didn't have a flashing-light system to alert swimmers to the start of a race; instead they used flags. The fifty free is a short race, so the start is crucial. I got off to a slow start, so I lost the race before it began.

In competitions, when I was a kid, they usually announced the start of a race into a microphone. My father or mother would stand behind me and tap me on the shoulder when it was time to start—usually, it was my mom, because she had a faster reaction time than my dad. Or, if I were doing the back stroke, they would stand in front of me and tell me to go. But, of course, I was always a late starter.

Photo: Tim Morse, courtesy of Harvard Sports Information

Now, many pools have a strobe-light signaler that comes with the timing system for competitions. I don't think Harvard had one before I arrived, but the coach ordered it immediately when she knew I was coming. When we travel to other schools, we always call ahead to make sure that the school has a strobe ready to use. With a strobe light to signal the beginning of a race, I am a very fast starter. In fact, I normally go out first because light travels faster than sound—I react to the light; the hearing swimmers react to the buzzer. Since I'm such a fast starter, my coach likes to put me in the first position on the relay.

I am having a great time swimming at Harvard. Before college, I sometimes had problems with some of my teammates—usually boys. They tended to pick on me. I decided that if anything like that happened to me in college, I would refuse to swim. Now, I am enjoying being a member of a swim team for the very first time in my life. For example, I have an interpreter at practices, something I never had before. When I was younger, my parents didn't think I needed an interpreter at practices. They felt that I needed to learn how to communicate with hearing people, you know, like in the "real world." I do things on my own with hearing friends without interpreters, but having an interpreter at practices really makes a difference. It has helped a lot in communication with my coach and with other swimmers, and I feel more like I am part of the team.

Avoid low expectations

I would like to tell parents to make sure that their children are not limited by low expectations. Parental support is extremely important. There are a lot of bright deaf kids out there, but if the parents aren't behind them, their educational supports will fall through and they will never reach their full potential.

Photo: Michael Fein

When I was young, my parents really benefited from meeting and talking with parents of older deaf children. For example, one summer, they went to a "Family Learning Vacation" (FLV) at Gallaudet University. This was before my brother was born. Since I was deaf, my parents were not sure if they should have another child; they didn't know if it would work out to have a deaf child and a younger, hearing sibling. Through meeting other parents at the FLV, my parents were able to see that it had worked out fine for others.

Other parents helped my parents a lot; now my parents help others. When I was growing up, my father became involved with the board of directors of the American Society of Deaf Children. He was the president of the PTA at the deaf school. Almost every year, the teachers at the deaf school would ask my parents to come in to talk to parents of new students about what it was like to have a deaf child. Even now, my first parent-infant teacher continues to refer parents of newly-diagnosed deaf children to my parents.

It is really important for parents of deaf children to know that they are not alone, and to know that their kids will be okay. Parents shouldn't think, "Oh my God, my kid is deaf! What a terrible thing!" Deaf kids can have good lives and contribute a lot to society.

417

Kate's Song

These pages feature the pictures and words of artist Michelle White. Michelle has used her considerable artistic talents to chronicle the life of her daughter Kate, who has Down syndrome. If a picture is worth a thousand words, these images speak volumes.

Birth Cry
Kate was born on November 1, 1989. I had refused to have an amniocentesis, so we did not know before Kate was born that she had Down syndrome. I don't regret my decision.

The Promise
Katie was a planned pregnancy. Both my husband and I believed that God wanted us to have a third child. It was very hard to understand when Kate was born with Down syndrome. After the grief and the tears, we came to peace with God and recognized Kate as a blessing, hence this drawing's title.

418

Bubbles
Kate delights in blowing bubbles. We first worked with her on blowing bubbles as part of her speech therapy; it was intended to help her mouth muscles develop. Now that she has the hang of it, she will sit for a long time and blow bubbles. It's pure joy to watch her.

Dad and Kate
Dad loves to toss Katie around and rough-house with her. She loves it, too.

John and Kate
In many ways, Johnny and Kate are typical siblings—one minute they are playing together nicely; the next minute, John teases Kate and the tears flow. Kate's limitations have been difficult for John to understand, because he is an exceptionally bright child.

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle # 26

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

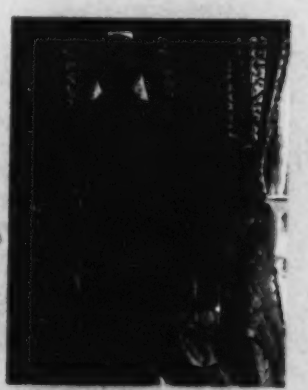
Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

See What I Can Do

I will never forget Katie's first checkup with her pediatrician. She was two weeks old and had severe hypotonia. Dr. Robinson picked her up, and we both watched her legs, arms and head dangle like those of a rag doll. Then, the doctor said, "She probably won't walk until she is four." This is Katie at two and a half, one month after she walked unassisted for the first time.



Michelle White lives in Holtwood, Pennsylvania with her husband, John, and children, Christin, 14; Johnny, 10 and Kate, 4. John is sales manager for WDAC Christian Radio in Lancaster. Kate attends the S. June Smith Center for children with developmental delays and a regular preschool program at Noah's Ark. Michelle has won numerous awards for her paintings, drawings and sculptures. Her recent works celebrate the human form and Christianity, and convey her belief in the sacredness and beauty of life. Michelle combines showings of her artwork on slides with speaking performances and music; she also does portraits. For more information, write to her at Hidden Hills Studio, 624 Hilldale Road, Holtwood, PA 17532.

420

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

Circle #18

1-800-600-7808, 1-800-755-0601(TTY). The Apple Computer Disability Solutions Store.

*Chris and the entire staff at Aisle 17 have talked to lots of people just like you. They're friendly, they're knowledgeable, they're ready to help.

PARENTS ONLINE

A few months ago, looking ahead to this special, telecommunications theme issue, and hoping to put a "human face" on the technology, I set out on the "information superhighway" looking for parents of children with disabilities. I got online and posted a few public invitations for parents to share their experiences with readers of *Exceptional Parent.*

To say simply that the response amazed me would be an understatement. The sheer numbers took me by surprise—more than 300 pieces of electronic mail ("e-mail") flooded my online mailbox. I was even less prepared for the incredible power and emotion of the stories these letters told... or for the words parents used to describe others they knew only through printed text on a computer screen—words like *close friends, family* and *community.*

Information and Support

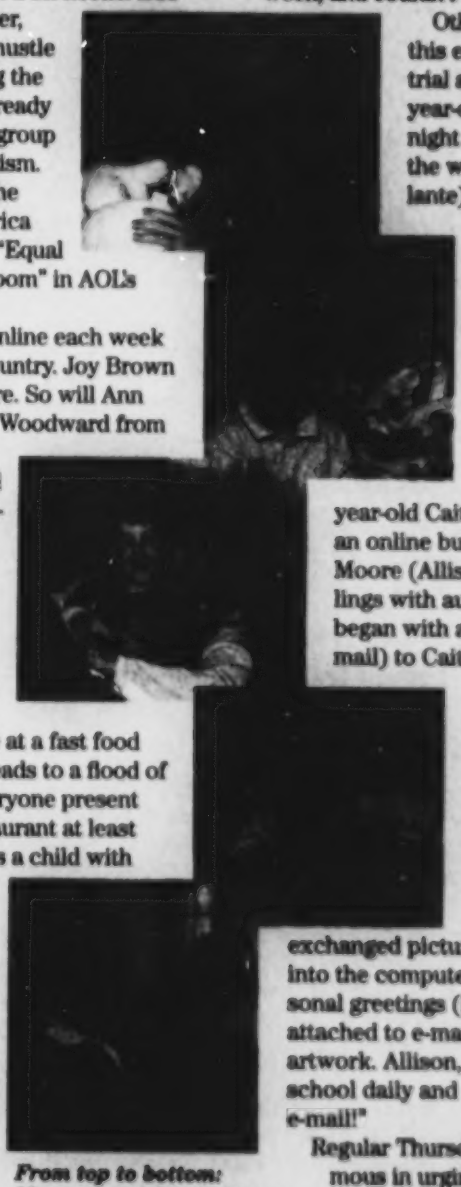
For many parents of children with disabilities, telecommunications may provide their first contacts with other families in similar circumstances. Patti is the mother of an adolescent daughter only recently diagnosed with Rett syndrome, a rare disorder affecting only girls. Doctors had considered her child autistic, but information Patti obtained from other parents on Prodigy's Medical Support Bulletin Board led her to suspect the Rett diagnosis, which was later confirmed. Patti credits her online friends for more than information, however—"When our daughter entered puberty, she went through a severe behavioral and physical regression. Without the sup-

AOL AUTISM "CHAT" GROUP

Thursday nights at the Dixon household in Hingham, Massachusetts can get a bit hectic. Bob and Lee try to eat an early dinner, wash the dishes promptly and hustle the kids off to bed. After setting the VCR to tape *Seinfeld*, they are ready to attend their weekly support group for parents of children with autism. Settling into chairs in front of the computer, they sign on to America Online (AOL) and head for the "Equal Access Café," an "online chat room" in AOL's disAbilities Forum.

Joining Bob and Lee Dixon online each week are parents from all over the country. Joy Brown of Mason City, Iowa will be there. So will Ann Gibbons from Maryland, Diane Woodward from Louisiana, Fred and Susan Moore from North Carolina and many others. Tonight, conversation among the 22 parents in the "café" touches easily on a variety of topics—one child's upcoming IEP meeting, a new book that another parent has just read, an embarrassing incident with an impatient child who did not want to wait in line at a fast food restaurant. This last anecdote leads to a flood of others; it seems that almost everyone present has been embarrassed in a restaurant at least once by a child—and not always a child with autism!

Bob (screen name, JBob74) and Lee (Margsmom) remember the first time they joined the Thursday night chat—"At the beginning, we just sat back and listened, fascinated that all the people behind the screen names seemed to know each other, and that the conversation was not unlike that which friends might have across the kitchen table. The subject was autism, but these people could laugh and cry together, talk about their families and plans for the weekend, and in between all the small talk, they could exchange valuable information about autism... We enjoyed 'eavesdropping' that first week, and couldn't wait to return!"



From top to bottom: Margaret and Caitlin Dixon; Stephen and Allison Moore; Joy Brown with son, Jamie; Jeremy Woodward, age four; Phillip Gibbons, age five.

Other regular participants share this enthusiasm. Jill (JillDJ), a busy trial attorney and the parent of four-year-old Zachary, calls the Thursday night chat "one of the highlights of the week." Diane Woodward (Parlante) agrees, "These meetings are an invaluable resource. I just can't emphasize that enough. 'Comparing notes' helps me to find out what is common among children with autism and what is unique about my child. It also helps to know I am not alone."

Online support is not limited only to parents. Nine-year-old Caitlin Dixon (CaitTheGr8) found an online buddy in six-year-old Allison Moore (AllisonCM). Both have younger siblings with autism. The girls' relationship began with a piece of electronic mail (e-mail) to Caitlin's dad, Bob, from Allison's father, Fred (AttyFred). Fred wrote that Allison, who sometimes considers younger brother Stephen "a pain," wanted to ask Caitlin if her sister, Margaret, also "got on her nerves." Caitlin, says her dad, "couldn't wait to reply." Since then, the girls have exchanged pictures of themselves (scanned into the computer and attached to e-mail), personal greetings (saved as "sound files" and attached to e-mail) and computer-generated artwork. Allison, says Fred, arrives home from school daily and says, "I need to go check my e-mail!"

Regular Thursday night chatters are unanimous in urging other parents to take the plunge into telecommunications. Joy Brown (Joyb837443) says that her experiences with telecommunications have been invaluable—"I would recommend this to anyone just for all the information that is available; the many friends you will make online is the icing on the cake!"

port we found online, we would never have been able to deal with it. I had started to resent my daughter. Actually, it had become difficult for me to summon up *any* feelings for her. My friends on the bulletin board helped me to understand what was happening during my daughter's regression. They helped me to reach out to her and love her. My online friends virtually gave us back our family."

Sally Wilson, the West Virginia mother of a four-year-old boy with autism, also appreciates the opportunity to speak with other parents of children with autism, especially those older than her son—"I have made a close online friend (although she lives far away) who has a six-year-old son very similar to mine. Recently, doctors suggested that it would help if I could find a parent with a high-functioning child who was about two years older than mine. Thanks to telecommunications, I could tell them, 'I already have!' I was one step ahead of the medical community. When will *they* catch up?"

Virginia Crimarco, a registered nurse and the mother of a nine-year-old child with phenylketonuria (PKU), is happy to provide support to parents of children younger than her own. In fact, she has been active in notifying hospitals about the online support that is available to new "PKU parents"—"Technology has made life easier for those with newly diagnosed infants. A new mom and dad, upset over a recent diagnosis, need only turn on their computer to find warm and compassionate people who have 'been there.' They never even have to leave the house!"

A Glimpse into the Future

Telecommunications also allows parents to make contact with adults who have disabilities, allowing them a glimpse into the futures of their own children. Heather RaVell Strafach is the mother of ten-month-old Will, who has albinism and is visually impaired. Although Will is very young, and the extent of his visual impairment is still unknown, Heather's online discussions with adults who are visually impaired or blind have made her more confident about his future—"In 'real life,' I don't know any people who are blind. Online, I have asked questions and learned so much. I cannot tell you how much this has meant to me!"

Robert "Bear" Eshelman, an adult who is visually impaired, says he welcomes the questions of parents like Heather—"Parents of a child who is blind wouldn't think about approaching me on the street, but online they are more comfortable and willing to ask questions. Parents should know that it is okay to ask questions; most of us are glad to help. There are many people with disabilities online who have years of experience that would be useful to parents."

Benefits Outweigh Risks

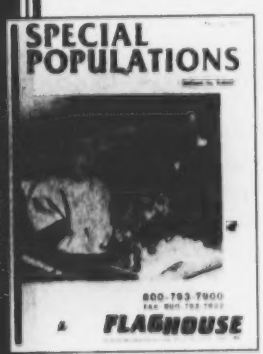
Although the parents I heard from were uniformly enthusiastic about the information and support they had found online, a few mentioned some pitfalls of electronic support. Donna Getz is a member of a family who has been dealing with the effects of neurofibromatosis type II (NF2) for several generations. Her husband and father-in-law are affected; so are two of the couples' three children. Donna asserts that "I would rather give up my microwave than my online support group—and I *really like* my microwave." But she warns that it is easy to become overwhelmed by the sudden onslaught of support, and over-involved in the lives of your new online friends—"After feeling 'on your own' for so long, it is easy to become an 'online junkie.' You can become very involved with the people you meet there. We have become very close to people who died from NF, or as a result of NF-related surgery. It's very upsetting when that happens. No question about it."

Of course, all close human relationships involve making ourselves vulnerable; friendships forged in "cyberspace" are no different. Donna, like most others, agreed that the incredible benefits of telecommunications outweighed its minimal risks.

–K.S.

FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE



Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- Aquatic Aids/Sports Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE INC.
150 No. MacQuesten Pkwy., Suite 95745, Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

Circle # 29

Getting Started with Telecommunications

by Peter Green

To many people, a personal computer is little more than a sophisticated typewriter with the ability to play video games. But nowadays, it may be more appropriate to think of a computer as a kind of enhanced telephone. By connecting a computer to your phone line, you can easily communicate—not only with your voice, but with pictures and written words, too.

For children with disabilities, and for their parents, this is no small achievement. When the subject is disability, communication—the sharing of questions, answers, ideas and information—isn't usually easy. Most parents of a child with spina bifida, for example, don't live in a community filled with other parents of children with spina bifida. Nor do most local libraries carry extensive collections of disability-related information. For parents of a child with a disability, exchanging information and meeting people in similar situations can be, at best, difficult.

Telecommunications can change all that.

An Electronic Community

In the literal sense, telecommunications refers to a bunch of wires, computer chips and telephones working together to connect computers with one another. But what telecommunications represents is nothing short of an electronic community—a place where the post office never closes, where there are ongoing seminars about every conceivable topic and where very generous libraries give away information instead of loaning it. It's a community where people cannot see one another, so they care more about *what* is being said than *who* is doing the saying. It's a community that you can plug into, or disengage from, whenever you choose.

Perhaps most importantly, telecommunications is a chance for everyone to present themselves as they would like to be perceived. A computer is able to level the playing field like no other tool. It doesn't care what you look like, what you sound like or how old you are. Unless you choose to make these characteristics known, the person with whom you are communicating isn't able to judge you based on anything other than what you have to say and how you express it.

First Things First

Especially if you are new to computers, it makes sense to learn about telecommunications from someone who has experience—a student at a nearby university, a colleague at work, another parent or a counselor at a local technology resource center. Before jumping into the middle of any new community of people, it helps to have someone show you around town.

It also helps to have some understanding of the place you're visiting. Who *are* the people in this electronic community? How does your computer help you travel there? And where *is* "there," anyway? To answer these kinds of questions, the following overview describes what happens behind the scenes when you use your computer to plug into a commercial online service:

Somewhere, often in some remote part of the country, sits a big computer, packed with information. This computer—the online information service—acts as the central meeting place for people from all around the world, a place where kids and adults gather to chat and retrieve information. Of course, people don't actually travel to this remote place to meet in the shadow of this computer. Instead, they call the computer using regular telephone lines in their homes and offices (usually, only a local phone call is required). It is through these phone lines that information—words, pictures and sounds—passes from the main computer to your personal computer, and vice versa.

Because telephone lines are naturally designed to handle voices rather than written words and pictures, you need something called a "modem" to connect to this central computer. A modem is a small computer accessory that makes it possible for all types of digital information—the form used in computerized communications—to be carried across normal phone lines.

Getting Started

You need only four things to get started:

1) A phone line;
2) A personal computer system;
3) A modem; and
4) A subscription to an online information service.

426

Assuming that you already have a phone line, your first challenge may be to locate a computer that you can use. If you have one at work, using it may be the most convenient and affordable solution—buying a new personal computer, with accessories, can cost from $1,000 to $3,000.

If a child with a disability will also be using the computer, accessibility is another important consideration. Your state's Alliance for Technology Access center or assistive technology program—see directories in January 1994 *Exceptional Parent*—can help you come up with accessibility solutions.

Making the Connection

Once you have access to a personal computer system, you'll need to make sure that it has a modem. Sometimes modems come with computer systems, but often they do not. So, how do you go about finding one?

First, do not feel like you must immerse yourself in modem minutiae. Consult with a friend or ask someone at your local computer store for a recommendation. Be sure to tell them three things: 1) the type of computer you have, 2) that you plan to connect to a standard online information service and 3) that you want a "14,400-baud" modem (baud is a measurement of the modem's speed—14,400 is just about the fastest modem you can buy, and it offers the best performance for its price). You may also want to indicate a price range—most modems of this caliber cost between $150 and $250. Not surprisingly, name-brand modems usually cost a bit more, but also tend to include the useful extras like cables, software and customer support.

The last thing you'll need is an account on a online information service. For most people, there's no better place to start than a *commercial* online service like America Online, CompuServe, Delphi, eWorld, GEnie or Prodigy. Most come with user-friendly software, and all have toll-free customer-support helplines.

Some people may balk at the notion of paying for an account on a commercial online service when there are thousands of "free" online services, or "electronic bulletin boards," in existence (see *Disability-Related Electronic Bulletin Boards*, page 39). And almost everyone has heard of the most famous "free" service of all—the Internet (see *Cruising the Internet*, page 33). But, unless you are an experienced computer user, connecting to these kinds of services can be difficult. Such services do not come with user-friendly software, so you'll need to use the communi-

CAROL HONEYCUTT
E-mail: VHMX40B@prodigy.com

My three-year-old daughter was a two-pound, one-ounce preemie who had an intracranial hemorrhage and has been diagnosed with Dandy-Walker syndrome. Her speech and gross-motor skills are delayed, and she has cerebral palsy. Katie had her first shunt placed while she was still in the NICU. Her first and only—knock on wood—revision was done seven months later.

Carol Honeycutt and Katie, age two.

Until that point, my mind had been dealing only with her prematurity and its associated problems. But, after I got over the trauma of Katie's shunt revision and the emergency that surrounded it, I realized that this thing called hydrocephalus would not go away. Thus began my frustrating journey for knowledge. Most articles were written for doctors in language I didn't understand. Publications for parents were few and hard to find.

Finally, I met a woman who told me about the Medical Support Bulletin Board on Prodigy. Computers? Bulletin boards? This was all Greek to me— I put my husband on the phone to get instructions.

What a lifeline that wonderful woman threw us! On the board, I found the education and support I was seeking. The people I met there are caring, supportive and knowledgeable. Some are parents and some are living with hydrocephalus themselves. I felt like I had stepped out of the darkness into the light.

Now, I feel ready to meet any challenge, ready to be a part of my daughter's support team. These people also help me to laugh. In this world of incomplete families, these people have become our extended family.

I would like to add that my husband reads the board as much as me. Men often find it difficult to deal with imperfection, with the frustration of not being able to "fix it." The board has been a wonderful outlet for him also.

Carol Honeycutt lives in Burtonsville, Maryland.

LANDON HAMLIN
E-mail: 70431.3577@CompuServe.COM

In January of 1992, my 19-month-old son, Luciano, contracted bacterial meningitis, resulting in a profound, bilateral hearing loss. My desire to find answers for my son led me to join CompuServe's Disabilities+ Forum, where I began scanning messages and searching online libraries for information. At some point, I introduced myself as a parent and indicated that I would appreciate some guidance.

The online community has provided support through networking with other parents and individuals with hearing impairments. These people have shared their experiences with me—sometimes lending a sympathetic ear, other times providing a contrasting opinion against which to weigh my own. I have found friends from as far away as Ontario, Canada and San Francisco, California who share otherwise unavailable resources. I have been informed of upcoming conferences and technological advances, sometimes even before the professionals who are involved with my son.

Shortly before I discovered this online community, a friend had loaned me *What's That Pig Outdoors*, the autobiography of Henry Kisor, a man who, like my son, lost his hearing to meningitis as a child. It was a tremendous thrill to find this bright and humorous man online, sharing words of wit and wisdom.

Landon Hamlin and son, Luciano.

I think the most valuable aspect of my online experience is the sense of control it gives me in dealing with my son's hearing loss. Parents in our circumstances feel a tremendous need to do something positive; especially in the beginning, there is always the feeling that one is not doing enough. Telecommunications gave me the information I needed to do all that I could for my son and the confidence that came from knowing that I wasn't simply trusting his care to someone else. No other medium offers such a broad spectrum of information in such a timely manner.

Landon Hamlin lives in Apopka, Florida.

cations software that came with your modem. This means dealing with setting "baud rate," "stop bits" and "parity." Once you have some telecommunications experience under your belt, these types of services can offer a wealth of good information. But unless you have an experienced mentor, or you're very adventurous and not easily frustrated, "free" services are not the best place to start.

Selecting a Service

In many respects, commercial online information services do not differ greatly. They all offer similar kinds of information—news, forums on various subjects, topical discussions and information databases—and all have the same basic underlying features including the ability to send and receive personal messages, post public notices and search information libraries. Most also offer the capability to chat "live" with other users, retrieve computer software and purchase items from an electronic catalog of products.

The capacity for users to send and receive electronic mail, or e-mail, is one important feature that all online systems have in common. E-mail refers to private messages that you can write and send instantaneously to other computer users. Many users cite their e-mail accounts as the most important benefit of online communication. E-mail is popular because it's fast, easy and fun. And, unlike conventional mail services—disparagingly referred to as "snail mail"—e-mail can be sent and received at any time of the day or night.

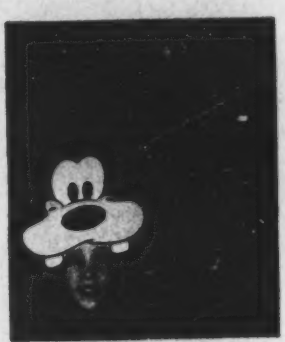
Two important factors, however, differentiate online services from one another: ease-of-use and the *specific* kinds of information that are available. A closer look at two popular commercial services—America Online and CompuServe—provides an illustrative comparison.

America Online is considered easy to use because its software provides graphics as a guide to moving around the service. For example, clicking your computer's mouse on a colorful picture of a newspaper takes you to a news forum, while the picture of an airplane represents an area dedicated to the discussion of travel tips. (Not incidentally, while these types of "graphic user interfaces" can be helpful for many people, they pose special problems for people who are blind.) CompuServe, on the other hand, is considered a more "text-based" service; users who do not have the service's special graphical-interface software must navigate from area to area within the service by typing commands. Though CompuServe does not use graphics in exactly the same way as America Online, it features an exhaustive 2,000 discussion forums on everything from fly fishing to legal advice.

CINDY PRICE
E-mail: BXRT89C@prodigy.com

My husband and I have six children—yes six, all ours! Our youngest son, Evan, has spina bifida, hydrocephalus and renal tubular acidosis.

I have been "hooked" on telecommunications since my older son got Prodigy for a Christmas present about a year and a half ago. My online "spina bifida family" has been very supportive through all the ups and downs. It is great to get online and post a note, and know that people who understand will reply. This support was especially helpful as I went through a very difficult IEP process trying to get Evan into a regular classroom. The encouragement I received from my online friends helped me to be confident that what I wanted for my child really was the best thing. It's been wonderful to share our joys, accomplishments and sorrows. It also feels good to be able to offer support to others.



Cindy and Evan ("Goofy") Price celebrate Halloween, 1992.

Last year, all of us sent family pictures to one of the mothers in the online group; she put all the photos together in a collage and had it photocopied—in color, no less. Each person who had sent a picture received one of the "albums." It was very exciting to finally see what everyone looked like. Our group is quite diverse—it includes adults with spina bifida; college-age kids; parents with brand new babies, toddlers and teens; even a very loving grandma.

I would encourage parents who are not yet online to give it a try. If I can do it, anyone can. Many of the commercial online services are very user-friendly for those, like myself, who are not very computer literate. It is great to be able to sit at home and have your very own support group that you can attend in your spare time.

Cindy Price lives in Grover Beach, California.

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet

The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 11

Sure, Jessica Radtke likes school, but like most 8 1/2-year-olds, she *loves* recess. Although she's good at dodgeball and baseball, you can see she excels at tetherball. As a three-year-old, Jessica was one of the youngest children in California certified to operate a power chair. At six, Jessica was enrolled in public school and

immediately helped therapists teach other young students how to control their power wheelchairs. Jessica is currently a third grader at Centerville School. Here she demonstrates her power and agility in her Zippie P500.

QUICKIE
The RealChair People

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
(609) 346-3300 • FAX (609) 435-4223
Brochure or video available upon request.

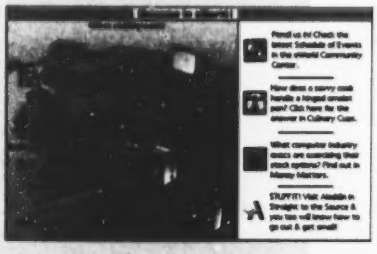
"Accreditation with Commendation"
Joint Commission on Accreditation of Hospital Organizations
Member: National Association of Children's Hospitals and Related Institutions

Circle # 85

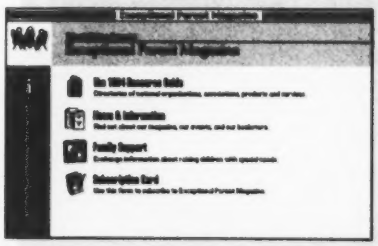
EXCEPTIONAL PARENT Announces Forum on eWorld

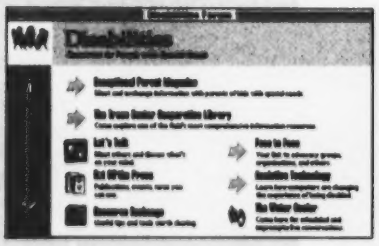
Exceptional Parent **magazine is collaborating with Apple Computer, Inc. to develop an exciting electronic forum on eWorld, Apple's new commercial online information service.**

eWorld, which will be available this summer, is a state-of-the-art online service that uses computer graphics to make communication and information retrieval fast and easy. There are eight main buildings on the eWorld globe—E-mail Center, Newsstand, Marketplace, Arts & Leisure Pavilion, Learning Center, Computer Center, Community Center and a Business and Finance Center. Each area uses distinctive graphics and a standardized user interface to guide the subscriber around the service.



The *Exceptional Parent* forum will contain three main components: an interactive message area for adults and children, a fully searchable database containing resource information and a bulletin board containing a variety of helpful documents. The *Exceptional Parent* forum is part of a larger eWorld "Disabilities" forum which includes participation from several other organizations, including: Trace R&D Center, ABLEDATA, Telecommunications for the Deaf, Inc., Special Needs Project, National Center on Accessible Media and Don Johnston Incorporated.





You'll learn more about eWorld—and the new *Exceptional Parent* forum—in upcoming issues of this magazine.

432

Commercial Online Information Services

AMERICA ONLINE
Pricing: No setup fee; $9.95/month (includes 5 free hours; $3.50 each add. hour).
Look/Feel: Graphics (requires special software)
Membership (approx.): 700,000
Disability-related information:
- disAbilities forum (message boards, online chats and software libraries)
- Assistive Technology forum
- National Multiple Sclerosis Society
- United Cerebral Palsy Associations
- National Alliance for Mentally Ill

Contact: 800-827-6364

COMPUSERVE
Pricing: $39.95 one-time setup fee; $8.95/month for basic services; $4.80/hour or $9.60/hour (depending on modem speed) for non-basic services).
Look/Feel: Text or Graphics (requires special software)
Membership (approx.): 1.7 Million
Disability-related information:
- Disabilities+ Forum (live chats, message boards, software libraries)
- Handicapped Users Database (HUD)

Contact: 800-848-8199

DELPHI
Pricing: No setup fee; $10/month (includes 4 free hours; $4 each add. hour) or $19 one-time setup fee; $20/month (includes 20 free hours; $1.80 each add. hour).
$3/month add. for Internet access.
Look/Feel: Text
Membership (approx.): N/A
Disability-related information:
- Access to WIDnet managed by the World Institute on Disability (online chats, conferencing, file libraries, message boards)

Contact: 800-695-4005

eWORLD
Pricing: No setup fee; $8.95/month (includes 2 free hours; $4.95–7.90 each add. hour).
Look/Feel: Graphics (requires special software)
Membership (approx.): N/A (new service to be launched in Summer 1994)
Disability-related information:
- *Exceptional Parent* forum
- ABLEDATA, RehabData libraries
- Trace Center Information Library
- Special Needs Project Bookstore
- Telecommunications for the Deaf, Inc. forum
- Software libraries, message boards, chat rooms
- Assistive Technology Center

Contact: 800-775-4556

GENIE
Pricing: No setup fee; $8.95/month (includes 4 free hours; $3.00–9.50 each add. hour).
Look/Feel: Text
Membership (approx.): 300,000
Disability-related information:
- Disabilities Roundtable

Contact: 800-638-9636

PRODIGY
Pricing: $4.95 one-time setup fee; $14.95/month for "core" services and 5 hours of "plus" services; $3.60 each add. "plus" hour.
Look/Feel: Graphics (requires special software)
Membership (approx.): 2 Million
Disability-related information:
- Medical Support Bulletin Board (many different topics and subjects)—5 free hours per month, then $1.20/hr
- "Parenting Special Needs" Topic on Homelife Bulletin Board (a "plus" service)

Contact: 800-776-3449

Like communities of people all over the world, electronic communities have their own reputations. Because it's easy to use, America Online tends to attract consumers who are new to the field of telecommunications or less "computer-literate." CompuServe, because it has been in existence longer and because its software is more difficult to use, has a reputation for attracting more technically sophisticated users.

The Bottom Line: Content

While many online services may look and even act alike, the information they offer may be quite different. Often, information from a particular organization or publisher is available only on one online service. Comparing the same two services as above, only America Online has access to information provided by *Time* magazine and files from the United Cerebral Palsy Associations. CompuServe, in turn, offers exclu-

EILEEN NAUSS
E-mail: NKSJ63A@prodigy.com

I am the parent of a seven-year-old boy who is deaf and has hydrocephalus. Patrick has had 17 shunt revisions over the last two years. At this point, he is doing very well. He is finishing first grade, and his first year in a mainstream classroom.

I have been active on the Prodigy "Hydro" board for 18 months. The support I have found there has been quite profound. In fact, we have become a family.

Patrick Nauss, age seven

The board has participants who are adults, and this is so important to me. On the board, I can talk to people with hydrocephalus who have gone to college, married and have kids of their own. As a parent, my biggest challenge is to treat Patrick as if he were a normal child. At the same time, I need to deal with the reality that he could face yet another surgery tomorrow—our kids need functioning shunts to survive.

I feel particularly empowered by members who relate their own experiences and share their fears as well as their successes. For example, it is a wonderful thing that Patrick is able to play baseball, but I had many talks with my friends on the board about my fears related to his safety. I think it is vital that I have people to share these feelings with; after all, this really is my problem and not Patrick's. I had to consider the opinions of the adults on the board who have strong feelings about the effects of "overprotective parents." It is this kind of day-to-day support that is so important to me.

Eileen Nauss lives in LaGrange, Illinois.

Rehab Technology One Stop Shopping

- Augmentative Communication
- Customized Mobility Equipment
- Seating and Positioning
- Funding Reports and Justifications
- Adapted Toys
- Orthotics

Children's Specialized, the state's only pediatric rehabilitation hospital, provides inpatient and outpatient treatment for children and adolescents, newborns to 21 years old.

Speak with the Specialists at Children's Specialized.

CHILDREN'S SPECIALIZED HOSPITAL

CSH-OCEAN
94 Stevens Road
Toms River NJ 08755
(908) 914-1100

150 New Providence Road
Mountainside NJ 07092
(908) 233-3720

CSH-Outpatient Center
330 South Avenue
Fanwood, NJ 07023
(908) 233-3720

Circle # 185

sive access to Roger Ebert's collection of movie reviews and a unique library called the *Handicapped Users Database.*

The comparison chart on page 31 lists six major commercial online services with information about how to contact them, their cost, and the types of disability-related resources they offer. None of these systems, of course, caters solely to the topic of disabilities. Commercial services, by definition, have large selections of diverse information.

Looking Ahead

What lies ahead for the rapidly-evolving field of telecommunications? In the short term, it is expected that more information (both disability-related and otherwise) will become available. Information providers including organizations, magazines, retailers and product developers are racing to explore the benefits of making their information available electronically.

Computer-based telecommunications will never replace natural, human interaction. However, at its best, this technology empowers people to expand their world—and to break their isolation—by opening new avenues of communication.

Peter Green lives in Boulder, Colorado, and is part of Apple Computer's Worldwide Disability Solutions Group. He co-authored, with Alan J. Brightman, the book INDEPENDENCE DAY: DESIGNING COMPUTER SOLUTIONS FOR INDIVIDUALS WITH DISABILITY *(1990, DLM).*

CRUISING THE INTERNET

by Bill McGarry

The largest electronic network in the world, the Internet, is actually a world-wide web of interconnected networks. The Internet is growing at a tremendous rate; a new network is added every ten minutes. It is nearly impossible to know how many people are connected to the Internet—some estimate that there are more than 15 million users in 140 countries.

Mailing Lists and Newsgroups

A variety of resources are available on the Internet. The most common is electronic mail or "e-mail." Almost everyone on the Internet has their own mailbox where e-mail can be sent directly. E-mail can be used for private discussions between Internet users. Internet users can also add their e-mail addresses to—"subscribe to"—any one of several thousand electronic mailing lists. Mailing lists allow subscribers to participate in ongoing discussions of almost any imaginable topic. Any message sent to a mailing list is mailed to every subscriber; individual subscribers can respond to messages or enter new messages which will, in turn, be sent to every subscriber. See sidebar for a partial list of disability-related mailing lists.

Many mailing lists also store all messages in a database at a central location. This allows users to search previous messages by using a "keyword." For example, I was recently contacted by someone who was looking for information on a program where dolphins were used in therapy with children who had mental retardation. Using the keyword "dolphin," I was able to search a database storing the last 30,000 messages posted to the Handicap Digest mailing list. Within a few minutes, an article describing this therapy program was retrieved from the archives and mailed to my electronic mailbox.

The USENET network, which is part of the Internet, also has a collection of more than 5,000 discussion groups called "newsgroups." Newsgroups store messages on a computer in a central location. Users can read and reply to the messages from their own computers. Disability-related newsgroups include misc.handicap, alt.support.spina-bifida and alt.support.arthritis.

ALDER CASTANOLI
E-mail: Alderc@aol.com

My four-year-old son, Christopher, was diagnosed with attention deficit disorder (ADD) early this year. At first, my wife and I were ashamed and worried to have a "hyperactive" child.

I had just received a new Macintosh computer for my birthday, so I thought I would use it to try to learn something about ADD. I joined America Online (AOL) and started to get involved in "chats" with other parents of children with ADD and other disabilities. During one of these chats, I learned about an Internet mailing list for parents of children with ADD. I found out that I could subscribe to this list through my e-mail address on AOL.

In the few short months since subscribing to the ADD-Parents mailing list, I have learned that my child is not a freak. I now know that Christopher has a medical condition that is treatable through medication and behavior modification techniques, many of which I have learned about through e-mail exchanges with other parents on the list.

The ADD-Parents list includes parents from all over the US and Canada, so we can compare notes on special education laws and practices in various locations. When we have an especially trying day with our kids, we can share our frustrations by sending e-mail to the list; often, we will get rapid return e-mail with suggestions or, just as importantly, moral support. The particular computer service each individual member of the list uses is not important—we can receive e-mail from commercial services like CompuServe, America Online, Prodigy, GEnie or any other service that provides an Internet mailing address.

I have learned how to better be a father to my son. And thanks to the parents of older children on the mailing list, I also have learned about the challenges that lie ahead. I know about the potential pitfalls of elementary school and higher education, and I am ready to deal with problems as they arise.

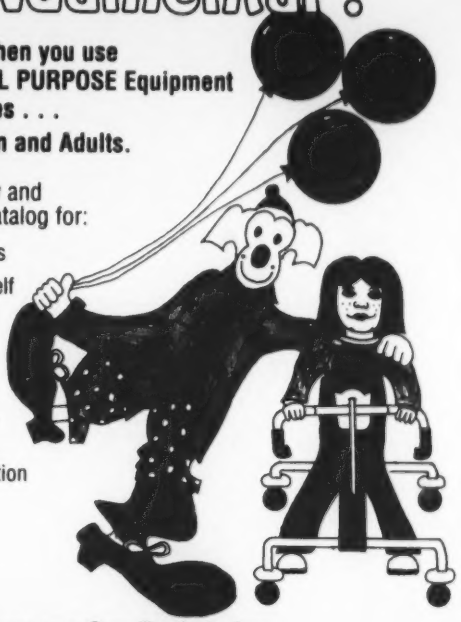
Alder Castanoli lives in Key West, Florida.

Is Your Therapy FUNdamental™?

It can be when you use our SPECIAL PURPOSE Equipment and Supplies . . .
For Children and Adults.

See our New and Expanded Catalog for:

- Mobility Aids
- Do-it-Yourself Supplies
- Positioning Furniture
- Wheelchair Accessories
- Learning & Communication Aids



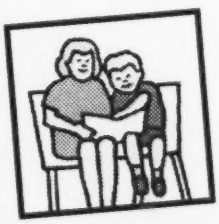
Since 1978

Consumer Care Products Inc.
810 N. Water St., P.O. Box 684
Sheboygan, WI 53082-0684
Tel: 414-459-8353
FAX: 414-459-9070

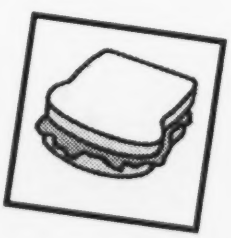
Circle # 109

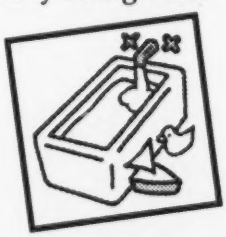
imaginart

Let us help you and your child with friendly, high quality materials:



- picture communication
- feeding and swallowing
- language development *featuring the Hanen Program*
- toys and games to train daily living skills





Pictures shown are communication stickers from our Pick 'n Stick Primary Pack.

Call or write for our free catalog:
Imaginart Communication Products
307 Arizona Street, Dept. EP4, Bisbee, AZ 85603
(800) 828-1376

Circle # 41

JEAN JASINSKI
E-mail: jean@swttools.fc.hp.com

About six years ago, my one-year-old daughter's leg hurt. Two months earlier, she'd had a similar episode involving the other leg. X-rays showed an old fracture in one leg and a healing fracture in the other. Since children this age do not commonly break bones, the doctors immediately suspected abuse.

I had just become pregnant with our second child when Kayla was diagnosed with a rare, genetic, brittle-bone disorder called osteogenesis imperfecta (OI). The doctors did not give us any written information, nor could they put us in contact with any other families who had children with the disorder. They were unable to tell me the odds of our next child also having OI, but advised that we have ultrasounds to look for in-utero fractures.

Our son, Jason, was born fracture-free and Kayla did not break any bones for almost another year. During that year, we searched for information about osteogenesis imperfecta, combing medical textbooks and asking all new doctors who crossed our paths what they could tell us about OI.

When Kayla started fracturing again, the need for information became greater. I had access to the Internet through work, so I posted a query to a few Internet newsgroups and ended up with a list of resources through which we were able to amass a great deal of medical, practical and personal information about living with OI.

When Jason passed his first birthday without any fractures, we breathed a huge sigh of relief. But as he grew older, it became clear that his development was delayed. He was diagnosed with sensory integration disorder and began occupational therapy. When my husband and I ran out of ideas for dealing with a minor behavior problem, I again went hitchhiking on the infor-

Retrieving Information

Many computer sites on the Internet offer free access to file libraries of software and text files. One such site at Olivetti North America is devoted to disability-related information and has more than 1,000 programs and information files. Some of the programs are free or "shareware"—if you like the program, you pay the author directly. Available programs include a sign language tutor, programs that allow the use of a computer with one finger, word predictors and speech synthesizer drivers.

The Internet has so much available information that it can become difficult to find what you are looking for. To make it easier to find and retrieve information

mation highway, looking for other solutions. This time, a woman answered my query, and we started corresponding via e-mail. Her son had also been diagnosed with sensory integration disorder, but was now considered to have autism. We compared notes and found that our sons were very similar. Eventually, we traveled from Colorado to New Jersey to have Jason seen by the same experts who had evaluated this woman's son. Just before his fourth birthday, my son was diagnosed with mild-to-moderate autism.

Jean Jasinski with children, Kayla and Jason, at Disneyland.

Two years later, this woman and I still correspond by e-mail several times a week. Besides meeting face-to-face on the trip when Jason was evaluated, we have attended one autism conference together and we will attend another soon. This time, we will be joined by another "electronic friend" from Minnesota, also the parent of a boy with autism.

My other friends can't understand what it is like to potty train a child who has autism. They have never dealt with a four-year-old who tantrums if you drive home via a different route. They don't comprehend the constant search for new treatments and therapies. My online friends give me the day-to-day support that can only come from someone who is going through the same things.

Jean Jasinski lives in Ft. Collins, Colorado.

and files, many sites now offer user-friendly utilities, including one called "Gopher" (named after the mascot of the University of Minnesota, where the program was first developed).

The Gopher program provides a single access point to the resources available on hundreds of Internet computers and presents all of the information in menu format. Instead of having to remember specific commands or recall the exact computer site where certain information is located, the Gopher program presents a menu of choices in plain English. Choosing one item on a menu may display a text file; another may get a software program from a file library, retrieve a picture, allow database searches or display another menu.

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support

The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 13

DISABILITY-RELATED INTERNET MAILING LISTS

The Internet offers a number of disability-related mailing lists. To participate in discussions taking place on a list, one must "subscribe" by sending a message to the list's distribution address (see below). The message should say simply (and without punctuation):

Subscribe LIST-NAME Your-Name

For example, to subscribe to the list for parents of children with attention deficit disorder, Alphus Jones would send a message to the distribution address, listserv@n7kbt.rain.com; his message would say:

Subscribe ADD-PARENTS Alphus Jones

He does not have to include his e-mail address in this message; the list administrator will get that information by looking at the "From:" line that will be automatically inserted at the top of his message.

List-Name	Topics of Discussion	Distribution Address
ADA-LAW	ADA, related legislation	listserv@vm1.nodak.edu
ADD-PARENTS	Children with ADD	listserv@n7kbt.rain.com
BEHAVIOR	Behavioral and Emotional Disorders in Children	listserv@asuvm.inre.asu.edu
BICOMPAL	Matches adults with disabilities as pen-pals of kids with the same disabilities	listserv@sjuvm.stjohns.edu
BLIND-L	Blindness	listserv@uafsysb.uark.edu
BLINDNWS	"Blind News Digest"	listserv@vm1.nodak.edu
BRAILLE	Braille	listserv@csearn.bitnet
BRAINTMR	Brain tumors	listserv@mitvma.mit.edu
COMMDIS	Communication disorders	listserv@rpitsvm.bitnet
CPALSY	Cerebral palsy	listserv@vm1.nodak.edu
CYSTIC-L	Cystic fibrosis	listserv@yalevm.cis.yale.edu
DADVOCAT	Fathers of children with disabilities	listserv@ukcc.uky.edu
DOWN-SYN	Down syndrome	listserv@vm1.nodak.edu
DDFIND-L	Information on disabilities	listserv@gitvm1.bitnet
DEAF	Deaf online magazine	deaf-request@clark.net
DEAF-L	Deafness	listserv@siucvmb.bitnet
DEAFBLND	Deaf and Blind	listserv@ukcc.uky.edu
DISRES-L	Research and disabilities	listserv@ryevm.ryerson.edu
DSSHE-L	Students with disabilities in higher education	listserv@ubvm.bitnet
IMMUNE	Immune disorders	immune-request@weber.ucsd.edu
LD-LIST	Learning disabilities	ls-list-request@east.pima.edu (Msg should say only: "Subscribe")
L-HCAP	"Handicap Digest"—general disabilities	listserv@vm1.nodak.edu
MD-LIST	Muscular dystrophy	md-list-requester@dataz.bisix.com
MOBILITY	Mobility disorders	listserv@sjuvm.stjohns.edu
MRDEAF-L	Mental retardation with deafness	majordomo@bga.com
RPLIST	Retinitis pigmentosa	rplist-request@irl.fr
STROKE-L	Strokes	listserv@ukcc.uky.edu
TBI-SPRT	Traumatic brain injury	listserv@sjuvm.stjohns.edu

Each choice on a menu will connect you to the computer where that information is stored, no matter where in the world it may be. The location of the information will be indicated.

Depending on the system you are using for Internet access, a single text command, menu selection or mouse-click on a Gopher icon will connect you to any Internet gopher site. For example, if you were to connect to the Gopher server at the Olivetti Disability Resource Center (gopher.afd.olivetti.com), the main menu would display a number of choices including: 1. Caution! Gopher Under Construction, 2. How to Find Your Way Through this Gopher, 3. Other Disability-Related Gophers, 4. Disability Resources, 5. Medical and Health Resources, and 6. Search the GopherSpace for Special Topics. If you were to select the fifth menu item, Medical and Health Resources, the Gopher would then display a multi-page menu with nearly 200 choices including a genetic engineering database in Italy, the World Health Organization in Switzerland and biomedical resources at Yale–New Haven Hospital.

The Internet has more than 7,000 Gopher sites, with 75 to 100 new sites being added weekly. More than 12 million items are available through Gopher. The amount of available disability-related information is growing rapidly.

Getting Internet Access

How do you get access to the Internet? Most universities and many companies offer access to students and employees. Most of the major commercial online services offer at least e-mail access to the Internet; some offer access to other Internet features as well. Other options for gaining Internet access include local bulletin boards, community-sponsored networks, called "Freenets," or commercial Internet

providers—most charge a flat monthly fee and provide a local access number.

Internet Resources

These books can tell you more about the Internet:

Dern, Daniel P. *The Internet Guide for New Users.* New York: McGraw-Hill, 1994.

Hahn, Harley & Rick Stout. *The Internet Complete Reference.* Berkeley: Osborne McGraw-Hill, 1993.

Levine, John R. and Carol Baroudi. *The Internet for Dummies.* San Mateo, California: IDG Books, 1993.

A number of useful electronic manuals are also available on the Internet itself, or from many commercial online services and local electronic bulletin board services.

Bill McGarry is the parent of three children, 11-year-old Alexander, who has Down syndrome, Meghan, 10, and Timmy, 7. He lives in Shelton, Connecticut and works as a computer programmer at Olivetti North America. McGarry is the system operator of the Handicap News BBS (203/926-6168, 300–14,400 baud) and moderator of the Disability Forum on National Videotex Network (NVN), a commercial online service. (For more information on NVN, call 1-800-336-9096.) Bill also moderates several Internet mailing lists and Fidonet conferences. He can be reached via e-mail at wtm@bunker.afd.olivetti.com.

DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS

The disability-related bulletin board services (BBSs) listed below can provide a wealth of helpful information. Use of all listed services is free, however, depending on where one lives, calling a BBS may incur long-distance telephone charges. A few bulletin boards charge fees for increased access or membership; when applicable, these fees are mentioned in the notes following each entry. Some boards chose to list voice numbers where the coordinator of the BBS, known as the system operator (sysop), can be reached for questions or comments.

These services do not provide special software, as do most major commercial online services. Instead, users must call the BBS using the communications software that comes with their modems. Users must be sure to stay within the given baud rate per second for modems (bps)—this figure is listed after the BBS modem number (i.e., "up to 9,600 bps"). This is the only aspect of the communications software that the user must configure (set) differently for various BBSs; the other modem settings are the same for all listed services—8 data bits, no parity, 1 stop bit (8-N-1). (These are the default settings for most communications software—you don't need to understand what each means; you may not even need to change the configuration of your software from the default.)

Once connected to a BBS, users can post and read messages, upload (post) and download (receive) files and leave messages for the sysop. Certain boards are connected to larger networks, such as Internet, Fidonet or ADAnet, which allow files to be shared and messages to be posted among a large number of bulletin boards.

ALABAMA

ADAnet
(205) 254-6050, up to 2,400 bps
All disabilities; many BBSs are linked to this system; many message areas, large file area for downloading; users get 30 free minutes daily; subscriptions ($40/yr) allow increased usage and unlimited downloading.

ALASKA

Assistive Technology of Alaska BBS
(800) 770-1399 (in AK), up to 2,400 bps
(907) 277-1399 (out-of-state), up to 2,400 bps
(800) 636-0138 (voice)
(907) 274-0136 (voice)
Forums on specific disabilities, education, assistive technology, legislation; files for downloading.

ARIZONA

Tucson Prologue
(602) 322-8014, up to 14,400 bps
General disabilities, some emphasis on blindness; Internet e-mail, Fidonet; message areas, files for downloading; local issues; most users are adults with disabilities.

CALIFORNIA

BayTalk
(415) 864-6430; up to 9,600 bps
Emphasis on computer-access issues for persons with disabilities; message/file areas concerning Americans with Disabilities Act, info for parents on local issues.

Blink Connection
(510) 276-4121, up to 2,400 bps
Emphasis on visual impairments; message areas; some Fidonet access; BBS can be used by persons with visual impairments.

Disabled Children's Computer Group
(510) 841-5621, up to 9,600 bps
(510) 841-3224 (voice)
Emphasis on children with disabilities; conferences for adults, families—parents are welcome; Fidonet; info on local resources, files for downloading.

KIRO Education BBS
(805) 324-2955, up to 14,400 bps
Emphasis on blindness, education; BBS use is free/$5.00 monthly fee for Internet access; Fidonet, Internet e-mail/newsgroups; National Federation of the Blind forums, publications online—helpful materials for parents.

LINCS–BBS
(408) 294-6933, up to 14,400 bps
(408) 277-0764, up to 14,400 bps
(408) 288-5010 (voice)
General disabilities, emphasis on children; Parents Helping Parents (PHP) members ($25 annual fee) receive Internet e-mail; message areas, "Parents Search" area, resource directories, info on rare conditions, local legislative updates; files/games for downloading; PHP can provide technical assistance to resource centers interested in starting their own BBSs.

CONNECTICUT

Handicap News BBS
(203) 926-6168, up to 14,400 bps
(203) 926-6187 (voice)
Wide range of disabilities—50–80 conference areas; Internet e-mail/newsgroups, Fidonet; many conferences helpful to parents, local conference available, although most callers are non-local, nearly 1000 files for downloading; sysop is parent of child who has Down syndrome.

DISTRICT OF COLUMBIA

ACB On-Line (American Council of the Blind)
(202) 331-1058, up to 14,400 bps
(202) 467-5081 (voice)
Emphasis on visual impairments; files on braille literacy, resource lists, archive of ACB literature.

ILLINOIS

COPH 2 BBS
(312) 436-0559, up to 2,400 bps
General disabilities; message areas, files for downloading.

INDIANA

The Special Needs BBS
(219) 659-0112, up to 14,400 bps
General disabilities, some emphasis on hearing impairments; Internet e-mail, Fidonet, health care net access; message areas for parents, files/programs for downloading; sysop is parent of child who is deaf.

LOUISIANA

Resource Access
(504) 897-9204, up to 2,400 bps
General disabilities; message areas, files for downloading.

MAINE

Maine Meeting Place BBS
(800) 339-3845 (ME only), up to 28,800 bps
(207) 324-5310 (Outside ME), up to 28,800 bps
(207) 324-2337 (voice)
Wide range of disabilities, related issues; BBS designed to accommodate computer novices—many parents are users; Internet e-mail/

DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS,

newsgroups; local issues; outreach to groups/individuals who need low-cost computer equipment.

MARYLAND

Braille Inn BBS
(410) 893-8944,
up to 9,600 bps
General disabilities; files in and about braille; Fidonet.

Deaf New World BBS
(301) 587-2277,
up to 14,400 bps
(301) 588-0965 (TTY)
(301) 588-0548 (Voice)
(301) 588-5261 (FAX)
TTY-compatible; thirty minutes free access daily—subscribers (varying rates) receive more time and Internet e-mail; emphasis on deafness; Fidonet; online shopping areas for deaf-related products; files for downloading.

HEX BBS
(301) 593-7357, up to 9,600 bps
TTY-compatible; general disabilities; Fidonet; message areas, files for downloading.

NFB Net (National Federation of the Blind)
(410) 752-5011, up to 14,400 bps
(410) 659-9314 (voice)
Emphasis on visual impairments; NFB literature, publications online, conferences for parents to discuss issues with adults who are blind; Fidonet, ADAnet; electronic books/text files for downloading.

MASSACHUSETTS

Disabled Individuals Movement for Equality Network (DIMENET)
(508) 880-5412, up to 14,400 bps
(513) 237-8360 (voice)
DIMENET is a coalition of Independent Living Center (ILC) BBSs working to obtain resources for online computing for all ILCs. The BBSs are based in Taunton, MA; Dayton, OH and Tulsa, OK; general disabilities, ILC related issues; Internet e-mail/newsgroups; Fidonet; files for downloading.

Mass. Commission for the Blind BBS
(617) 451-5327, up to 14,400 bps
(800) 392-6450 (voice, MA only)
(617) 727-5550 (voice)
Emphasis on visual impairments; message areas, conferences, employment info, conference info for parents; files for downloading.

BBS Directory continues on page 54

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Rueben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 66

KAREN BURKA

E-mail: ACUA16A@prodigy.com

Parenting a child with a disability is a time-demanding, all-consuming job. After you adjust to the fact of your child's disability, you try to pick up the pieces and get back to living a "normal life." But your life is far from normal. You spend all your free time—sick days, vacation time and personal days—going to speech therapy, medical specialists, IEP reviews and evaluations.

Karen Burka with Sarah and Mark.

I have two children with hearing impairments. Sarah is six and has only a moderate loss, but two-and-a-half-year-old Mark is profoundly deaf. Parenting a child with special needs means that I have to do twice as much with half as much time. I work full-time to cover the additional expenses and maintain health insurance, but end up with no time left for myself.

Telecommunications gives me the opportunity to quickly make contact with people who understand my situation, my decisions, my excitement when my son says a two-word sentence for the first time or my confusion over differing medical opinions and educational philosophies. If I get depressed because Mark's progress seems to be at a standstill, I can always find somebody out there to nudge me out of it and remind me to stay focused on those areas where he is excelling.

Besides making contact with other parents, I also get support from adults who are deaf. I can talk to deaf people through telecommunications, but would be unable to talk to them if they were standing right in front of me because I do not know American Sign Language.

Telecommunications allows people to be social again. Hectic lifestyles prevent us from going out and making contact with other parents just when we need it the most. I usually get on Prodigy late at night when the kids and my husband are asleep. Being on the board is therapeutic for me. Just reading all the messages, maybe responding to one or two, is like a catharsis.

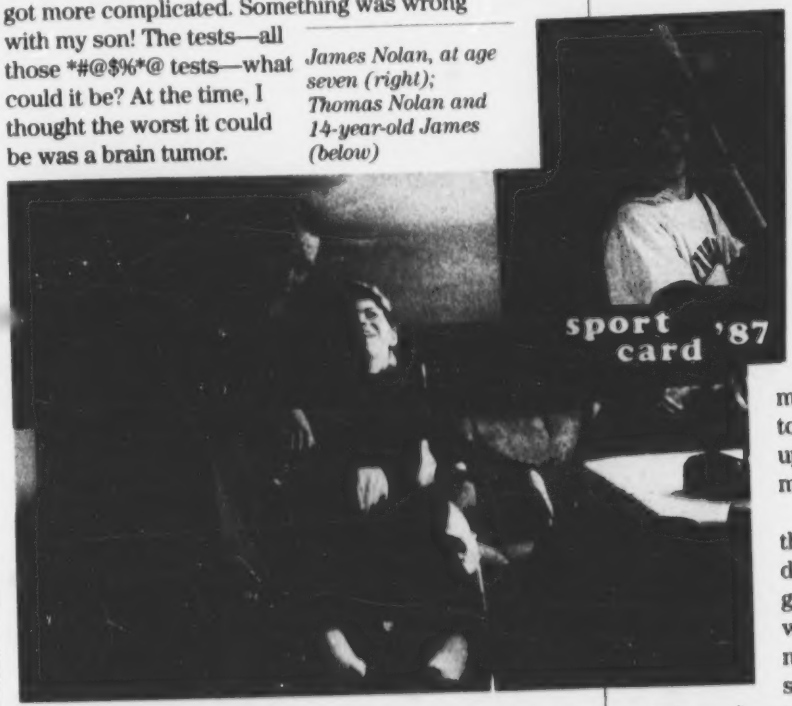
Karen Burka lives in Falls Church, Virginia.

440

What's a Tough Guy to Do?

by Thomas P. Nolan

James is my handsome, 14-year-old son. Our odyssey—or nightmare—began about seven years ago. One night, at a Little League baseball game, I noticed that James was not getting to the ball as quickly as usual. At the time, I didn't think much of this observation. As the months went by, however, things got more complicated. Something was wrong with my son! The tests—all those *#@$%*@ tests—what could it be? At the time, I thought the worst it could be was a brain tumor.



James Nolan, at age seven (right); Thomas Nolan and 14-year-old James (below)

Ha! Now, I wish it had been a brain tumor. After all the tests, the doctor told me that James had metachromatic leukodystrophy (MLD).

My first reaction was to ask how my wife, Carolyn, and I could fight this thing. Then, the doctor told us there was no cure! It felt like a ton of bricks had hit me. I became really angry and frustrated—what can a hard-living, tough guy do when there is nothing or no one to fight?

I went to work the next day bent on showing no signs of weakness. Then, someone asked me about our visit to the doctor. I broke down and cried—a big, macho guy crying uncontrollably.

How unmanly of me to be brought down by this! I was supposed to be the father, the strong one. Guess what—all the macho bullshit in the world is *zero pip-squeak* compared to having to tell your son he has MLD and is going to live a life of less and less until he dies at a very young age. For me, it was the end of dreams that were just dawning—there would be no more baseball games, no arriving home to be greeted by a boy who is jumping up and down and saying "let's play," no more toy stores.

I ended my work day with a stop at the old watering hole; I got stinking drunk while playing the role of a tough guy, but that only lasted for a little while. Reality set in at four or five the next morning when my son started screaming with pain in his legs. The pain in my heart prevailed over the pain in my head, but not by much.

The next day, I wanted to go and get drunk again, but something in my Neanderthal brain finally said, "No." I realized it was time to get on with the job at hand—taking care of my son, getting him up in the morning, dressing him, feeding him, changing him, carrying on both sides of our conversations, learning to play with him in new ways and putting him to bed at the end of each day—always the hardest time for me. Telling interesting bedtime stories had always been difficult; now it seemed almost impossible.

But along the way, I learned to be a more caring father for both of my sons. All those "womanly traits"

Thomas P. Nolan lives on Long Island, New York, with his wife, Carolyn, and sons, James and Brian. Thomas works as an auto body collision repair person, and is involved with programs of the United Leukodystrophy Foundation (2304 Highland Dr., Sycamore, IL 60178, 800/728-5483) and Candlelighters, a local support group for children with life-threatening illnesses or disorders.

441

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle # 75

I was so shocked to find within myself have helped me to survive the onslaught of emotional and physical demands leukodystrophy has thrust upon me. I must add that my older son, Brian, has benefited greatly from the United Leukodystrophy Foundation's sibling program. He has emerged as a "severely normal" 18-year-old young man. I love him very much; now, maybe more than ever.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth St., Bellevue WA 98008, (206) 747-4004; fax: (206) 747-1069. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda , MD.

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution

- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

Order Now by Calling 1-800-847-8887

Available in Black or Beige

TEMASEK TELEPHONE INC.
21 Airport Blvd. #G., So. San Francisco, CA 94080

Circle # 202

The Next Step Up In Wheelchair Mobility.

You're looking at scalamobil,™ a remarkable system designed to take on the toughest stairs. Fully automatic safety brakes. Only 42 pounds, it's half the weight of other systems. Folds to the size of a large briefcase.

For more about scalamobil and other alber® products, call and find out what's next.

TMI TECHNOMARKETING INC

307 Bacon Road • Rougemont North Carolina 27572 • (919) 477-1387 • Fax (919) 477-2294

©1994, TMI

Circle # 178

Empowering People with Disabilities and Their Families

by Carol H. Rasco

I come to you to express my deep commitment, and that of the Administration, to the empowerment of people with disabilities.*

Those of you who work in this field—whether as volunteers, professionals or family members—boost our determination and our capacity to resolve the tremendous challenges that remain before us. Your dedication and compassion inspires us to embrace the responsibility of meeting them.

As a parent who worked exclusively in this field as a volunteer until my son was seven, and who now works as a policy-maker, I want to tell you about some of the ideas and individuals that inspire me in my daily work. Although I will focus on health care reform, our reform agenda also extends from education reform to welfare reform, from safer streets to safer transitions to adulthood for all our youth.

Carol Rasco and son Hamp celebrate his 20th birthday. (Photo: Charles Archambault/Archambault Photography)

The White House Domestic Policy Council coordinates the efforts of the Administration, Cabinet secretaries and other federal agencies involved with the development of every aspect of our nation's domestic policy. As director of the Council's day-to-day work, I bring a strong determination that *all children shall be empowered to develop to their fullest potential.* To meet this crucial goal, our children need each of us to believe in them, and we as parents need the opportunities to nurture their growth.

As President Clinton recently stated, "Having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we are responding to the President's call to "craft policies of inclusion, independence and empowerment that will inspire positive changes in this country and in nations around the world."

Health care reform is an indispensable part of that mission. The President's health care plan is a dramatic advance for people with disabilities and their families. Here's why:

- It guarantees universal coverage for all Americans, and the peace of mind of having health care that is always there.
- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or become disabled.
- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.
- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable for the self-employed and subsidized for the unemployed. As a result, no one will be uninsured, even if they or members of their family experience a disability, injury or sickness.
- It offers a nationally uniform and comprehensive benefit package—in contrast to some of the other legislative proposals—that includes a range of preventive services, doctor and hospital visits, outpatient rehabilitation, home health care, adapted durable medical equipment (including orthotic and prosthetic devices and training in their use), mental health services, and many other essential services.

Furthermore, under Senator Edward Kennedy's proposal—now in congressional committee markup—outpatient rehabilitation services would be available to those who need them to restore capacity or minimize limitations as a result of illness, injury, "disorder or other health condition." And to maintain functioning or to prevent or minimize deterioration, rehabilitation services would be provided through a four-step process—initial evaluation and periodic oversight by a qualified rehabilitation health professional; design of a maintenance or prevention program; instructions for the patient, family members or support personnel to carry out the program; and patient reevaluations.

- It provides a major expansion of long-term care coverage by adding home- and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with dis-

* *This article is a revised and expanded version of remarks delivered by Ms. Rasco to the Arc Governmental Affairs Seminar, held in Washington, DC, on March 21, 1994. Nonprofit and disability organizations may freely make copies of this article for their members' information.*

abilities and their families benefiting from this new program, this coverage allows people with disabilities to live in their own homes—with their families, where appropriate—and to enjoy fuller and more satisfying lives.

- It adds significant civil rights protections for the enjoyment of health care benefits, consumer involvement in the design of the new home- and community-based services for individuals with disabilities, and health care "report cards" so that families can determine the health plan that best fits their needs and reward that plan with their membership.

The disability rights movement can play a critical role in this drive for universal coverage. On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President emphasized: "This is a battle that you may be able to lead for the rest of America… And so I ask you: Be an agent of change, an agent of empowerment. Never forget that you are carrying on your shoulders not only your cause, but ours as well. You can break through to those members of Congress. You can do it." From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial; then, on to lobby on Capital Hill.

Now is the time to guarantee health security for ourselves, for our children and for the generations to come. Without secure health coverage, too many of us are not free to change jobs, move to a different location or venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire a person with a disability or a person with a family member who has a disability.

These basic principles unite us. But it is our common love for our families that propels us to act.

Early in my son's life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of essayist and poet Joseph Addison: "Everyone must have something to do, someone to love, something to hope for."

I am constantly reminded of those words, not only for my son, Hamp, but for all the people with whom I've worked. In our quest to empower people, we must strive to fulfill these ends at each stage in life. In this process, we have myriad questions to ask and actions to take.

What do persons with disabilities have to do? For a young child, is a preschool program or other early intervention available? For a school-age child, is school relevant, safe and effective? Are our schools and transitional programs teaching both how to make a living and how to live? And, for adults, is there a job, day activity or voluntary service,that satisfies and excites? As President Clinton said in Memphis last November: "I do not believe we can repair the basic fabric of society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children… We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives." Those powerful thoughts are particularly apt for our citizens with disabilities who, too often, experience high rates of unemployment and underemployment.

What do persons with disabilities have to hope for? And what do we who love them have to hope for? Linda Charlton, the mother of a two-year-old daughter with Down syndrome, recently described her goals for her Katie before a superb and productive meeting of the President's Committee on Mental Retardation:

> "First, we want her to feel loved… to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There's even a part of us that hopes she'll continue her education after that… I wonder if she'll ever get married… if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today… Our Katie—who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red."

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son was asked last year by the members of his high school graduating class to give one of the commencement addresses. I will never forget that moment, nor will Hamp. Here was the young man whom we were once told would not survive or if he passed the hurdle of his first days, would have to be institutionalized. But Hamp defied those predictions, living at home and attending school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother's offer of help. Hamp said that this was his speech to give:

> "Hello, my name is Hamp Rasco. I am pleased to share with you what attending Hall High has meant to me.
>
> "I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria and going out into the community with my CBI class.
>
> "After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.
>
> "I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.
>
> "I want to thank Dr. Anderson and the vice principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work

HALF A LIFT IS *STILL* BETTER THAN WHOLE.

With maximum passenger seat maneuverability, a new easy off/on ground hugging platform, plus reliable all-electric operation.

The Crow River Industries VANGATER™ fold-in-half lift is a timeless classic. When folded it offers half a doorway of usable space for easy loading/unloading, more usable interior space, a clearer side view, and allows the front passenger seat to be almost fully reclined for maximum comfort. But we can't seem to stop trying to improve on perfection.

All-electric reliability.

The enclosed non-hydraulic, all-electric operating mechanism is cleaner and quieter than hydraulic lifts, especially in extreme temperatures. (There's also no leakage or unpleasant odor.) And our new auxiliary electric override provides emergency electrical lift power—not to mention peace of mind—when you need it most.

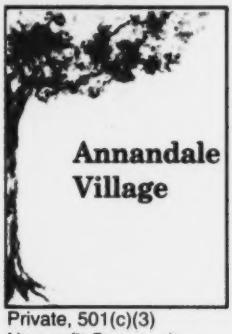
A flatter platform.

We've made getting on and off the VANGATER™ easier than ever with a new flatter platform that sacrifices nothing in ruggedness and reliability. And you'll find the improved side entry option and exit access great in tight parking situations!

RAPID RESPONSE LINE:
For more information and the name of your closest dealer call *today*:
1-800-488-7688

Circle #14

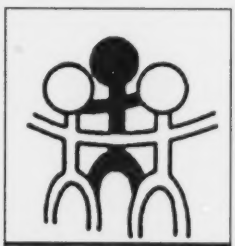
CROW RIVER™
Industries Incorporated
14800 28th Avenue North
Minneapolis, MN 55447 (U.S.A.)
(In Minnesota, 612-559-1680)



Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381



Camp Huntington

33rd Year

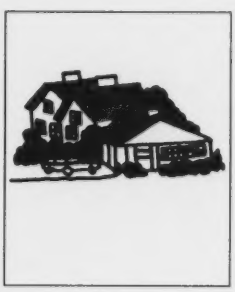
A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

THE DUVALL HOME, EST. 1945. A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:
- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874
(800) 358-0450



"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

they have done on my behalf and for all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be. I really hate to leave all my friends at Hall, but I must move on.

"Thank you. Good evening."

Like Hamp, we must all move on. Great challenges lie ahead, indeed. And as you well know, they are not limited to health care reform. From the White House to your house, we must work together. We need to reassure the countless young people like Hamp across this country that they will always have health insurance, that they can have jobs and that they are an essential part of life in our communities. For surely, to be whole and part of whole communities, people deserve something to do, someone to love and something to hope for.

The leaders of the disability community are campaigning to achieve these goals and objectives. I sincerely want to thank all those leaders, including Paul Marchand and the rest of Arc's Government Relations staff, for their hard work in fighting to bring health security to every American. In addition, I commend the 100 sister organizations united in the Consortium for Citizens with Disabilities for their steadfast support. Now, we must intensify those efforts. We must each tell our personal stories so that members of Congress have before them the human faces of health care reform. We need each of you to help seize this moment of opportunity to *guarantee private insurance for all our citizens—coverage that offers choice, comprehensive benefits and freedom from unfair and exclusionary insurance practices.*

I believe that a new day has dawned for America's citizens with disabilities and for all our people. We won't always succeed and we won't always be able to do everything that we want. But with your energy and resolve, we can have health security now. And I can promise you this: we will never relent in our effort to give every person a chance to develop—fully. Because, at the end of Bill Clinton's second term, at the start of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all of America, with a clear conscience and full heart—"We did our best." And for all our children's sakes, I want each of us to be able to look at one another and say—"We did our best."

Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is President Clinton's chief domestic policy adviser, coordinating the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco.

446

Augmentative and Alternative Communication Devices

This article will offer tips for parents about the purchase of highly-specialized augmentative and alternative communication (AAC) devices—self-contained units designed to meet the communication needs of children and adults who are unable to communicate through speech. This article will not discuss the use of general-purpose personal computers with accessories such as voice synthesizers and/or specialized software, even though such equipment can be very helpful in meeting the communication needs of some children.

The AlphaTalker™, manufactured by Prentke Romich Co., Wooster, OH

Before you buy...

Parents should consider a number of factors when considering the purchase of an AAC device:

• ***Team recommendations***—AAC equipment choices for a child should be based on a comprehensive evaluation by an experienced clinical team, usually including a speech-language pathologist, occupational therapist and physical therapist. This evaluation also should include the input of parents, classroom teachers and other professionals. Evaluations normally include an assessment of communication skills, physical abilities, intellectual abilities, and visual and auditory functioning. It also should consider the settings in which the device will be used. The child's abilities to use different devices can also be assessed at this time.

The Dynavox™, manufactured by Sentient Systems Technology, Inc., Pittsburgh, PA

Parents and the team can determine the best ways for the child to access an AAC device. A child may operate an AAC device with a standard or adapted keyboard, visual or auditory scanning, standard or sip-and-puff switch, touch-screen or joystick. Again, the team should consider both the child's current and future needs.

Parents and the team also can consider whether a "low-tech" system like a picture and/or alphabet communication board might work better for a child in some or all situations.

• ***Expandability***—A child's language abilities and educational and social needs will probably change over time. An AAC device should have the potential to meet the child's needs for the next few years. "Expandability" refers to the ease of adapting the device to the child's growing communications skills.

• ***Communication output***—Most children will want to communicate using both speech and print. Find out about the ease with which an AAC device can provide both speech and print, and evaluate the quality of each type of output.

Some AAC devices can be used to operate personal computers. Ask about this capability and find out whether additional equipment is required.

• ***Ease of operation***—It is important to find out how the device is programmed. "Programming" refers to customizing a device so it contains the vocabulary a specific child needs for communication. The device should be easy for key adults to program.

Although a device may look easy to operate, be sure to talk with other users of the product—both parents and children—to find out about their experiences. Other users can discuss the device's reliability, ease of "troubleshooting" when problems arise and vendor/manufacturer ability to repair the device quickly.

• ***Portability***—Find out if the system is portable and how easily it can be positioned in reference to the user. For a child who uses a wheelchair, find out about the ease of mounting the device on the chair—as well as removing it for those times when the child sits elsewhere. Some devices are heavy, 10 pounds or more, but will need to be transported with the child.

• ***Trial period***—Find out if there are a variety of similarly appropriate devices from different manufacturers. Whenever possible, have your child try each device at home, at school and in other environments where the device will be used.

Manufacturers of AAC Devices

AbleNet
1081 10th Ave, SE
Minneapolis, MN 55414-1312
(800) 322-0956
(612) 379-9143 (FAX)

ACS Technologies
1400 Lee Dr, Ste 3
Coraopolis, PA 15108-1205
(412) 264-2288
(412) 269-6675 (FAX)

Adaptech
ISU Research Park
2501 N Loop Dr
Ames, IA 50010
(800) 723-2783
(515) 296-9910 (FAX)

Adaptive Innovations
68 Hale Rd
E Walpole, MA 02032
(508) 660-2635
(508) 668-4134 (FAX)

Al Kalashian
3234 S Villa Cir
W Allis, WI 53227
(414) 327-4051

Baylor Biomedical Services
2625 Elm St, Ste 102
Dallas, TX 75226
(800) 365-1890

Canon USA
One Canon Plaza
Lake Success, NY 11042
(516) 488-6700

CP Research Foundation of Kansas
2021 N Old Manor
Wichita, KS 67208
(316) 688-1888
(316) 688-5687 (FAX)

Crestwood
6625 N Sidney Pl
Milwaukee, WI 53209-3259
(414) 352-5678
(414) 352-5679 (FAX)

Don Johnston
1000 N Rand Rd, Bldg 115
Wauconda, IL 60084-0639
(800) 999-4660
(708) 526-4177 (FAX)

Ekeg Electronics
PO Box 46199, Station 'D'
Vancouver, BC V6J 5G5
Canada
(604) 273-4358

continued

447

Manufacturers of AAC Devices, continued

F Keep
22501 Mt Eden Rd
Saratoga, CA 95070
(408) 248-2579

Imaginart Communication Products
307 Arizona St
Bisbee, AZ 85603
(800) 828-1376
(602) 432-5134 (FAX)
See ad on p. 36

Innocomp Innovative Computer Applications
26210 Emery Rd, Ste 302
Warrensville Heights, OH 44128
(800) 382-8622
(216) 464-3638 (FAX)

Intex Micro Systems
PO Box 12310
Birmingham, MI 48012
(313) 540-7601

InvoTek
700 W 20th St—ENRC
Fayetteville, AR 72701
(501) 575-7659
(501) 575-7446 (FAX)

Luminaud
8688 Tyler Blvd
Mentor, OH 44060
(216) 255-9082
(216) 255-2250 (FAX)

Mayer-Johnson
PO Box 1579
Solana Beach, CA 92075-1579
(619) 481-2489
(619) 550-0449 (FAX)

Mount Sinai Medical Center
Patient Representative Dept
1 Gustave L Levy Pl
New York, NY 10029
(212) 241-6920
(212) 996-2230 (FAX)

Pitts Corporation
4260 N 650 E
Provo, UT 84604
(801) 225-6441

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1984
(216) 263-4829 (FAX)

Sentient Systems
2100 Wharton St, Ste 630
Pittsburgh, PA 15203
(412) 682-0144
(412) 682-0241 (FAX)
see ad on p. 3

Tash
91 Station St
Ajax, ON L1S 3H2
CANADA
(905) 686-4129

TechnoGenesis
PO Box 11976
Prescott, AZ 86304
(602) 778-5611

Therapeutic Toys
PO Box 418
Moodus, CT 06469-0418
(800) 638-0676

TIGER Communication Systems
155 E Broad St, Ste 325
Rochester, NY 14604-1722
(800) 724-7301
(716) 454-3631 (FAX)

Toys For Special Children
385 Warburton Ave
Hastings-On-Hudson, NY 10706
(800) 832-8697

Words+
43700 17th St W, Ste 202
Lancaster, CA 93584
(800) 869-8521

Zygo Industries
PO Box 1008
Portland, OR 97207-1008
(800) 234-6006

Some manufacturers offer trial or rental periods; in some areas, there are equipment loan programs. Some manufacturers offer informative videotapes that show individuals with disabilities demonstrating the equipment's potential. Manufacturers can also put parents in touch with other users of the devices.

• ***Vendor support***—AAC devices are usually purchased from a local vendor who represents a manufacturer. Find out if the vendor will: 1) come to your home and/or child's school to assist in initial set-up; 2) come to your home and/or child's school to provide "hands-on" training; 3) provide additional training aids to help children and parents learn at their own pace and convenience; and 4) assist with problems or repairs.

Find out from the vendor, and other customers, whether the manufacturer will provide toll-free, around-the-clock telephone support for questions and problems; repairs within a reasonable time frame; and a clear, understandable warranty with available extended coverage.

Meet Other AAC Users

To make contact with consumers who rely on AAC, their family members and friends, contact: Hear Our Voices, 55-301 Hanover Circle South, Birmingham, AL 35205, (205) 930-9025, (205) 934-9459 fax. Professionals may be interested in the International Society for Augmentative and Alternative Communication (ISAAC), P.O. Box 1762, Station R, Toronto, Ontario, M4G 4A3 Canada, (905) 737-9308, (905) 737-0624, fax.

Thanks to the following for their contributions to this article:
Dick Bissegger, President, TechnoGenesis, Inc., Prescott, AZ
Joan Bruno, Ph.D., CCC-SLP, Manager, Augmentative Communication, Children's Specialized Hospital, Mountainside, NJ
Sharon Glennen, Ph.D., CCC-SLP, Director of Assistive Technology, Kennedy Krieger Institute, Baltimore, MD
Kathleen H. Miller, Ph.D., Partner, Consultants for Communication Technology, Pittsburgh, PA
Barry Romich, P.E., President, Prentke Romich Company, Wooster, OH
Ken Saban, Ph.D., Marketing Manager, Sentient Systems Technology, Inc., Pittsburgh, PA

At Devereux . . .
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

448

continued from page 15

I am concerned less about the academic problems of these children than their "social and emotional needs," as P.A.D. writes. No child benefits in a setting where he or she fails. Even children with severe disabilities usually know when they can't perform as others do; it generally pains them.

S.M. reports "no interest in how many graduates are employed or in post-secondary programs." However, a job is an essential part of inclusion in society. I am fortunate to work in a program which assists hundreds of persons with disabilities to find jobs each year. Their response to being employed cannot be understated. It brings great self-worth, dignity and independence. Education should seek, wherever appropriate, to lead to greater employment.

S.M. asks good questions about comparable data. The study I cited did not measure the failure rate of students without disabilities. It did include some related comparisons, however. The grade point average for children without disabilities is significantly higher than for children with disabilities in the same school setting (regular classes). Children with disabilities also drop out of school at significantly higher rates.

Two out of three high school students with learning disabilities failed at least one course, more frequently in their freshman and sophomore years; their dropout rates then accelerated. My point in reporting this data was to show that current efforts are inadequate—no one can wish to support a system where two out of three children experience failure.

S.M. uses the term "segregated" schools, which is why I wanted to "shake that foundation" a bit. It is overly simple to suggest that all special (read segregated) schools are bad and all integrated programs are good. It is possible to offer excellent programs or awful ones in either setting. I am not recommending a return to special schooling; in fact, only six to eight percent of all children with disabilities are in such settings. Rather, I suggested looking at successful special programs to see what we can learn in order to help the nine out of ten children in regular school-based programs succeed. Inclusion models can be successful, and we need to demonstrate that by carefully constructing and evaluating them.

To answer S.M.'s question about college attendance, college education does, in fact, correlate with successful acceptance into the community because it is correlated positively with employment, higher salaries and general independence. It is a good outcome measure, where appropriate to a given student's abilities.

Finally, I have also received personal responses to my editorial which presented additional views. In one, a father expressed concern that his school district is changing policy toward inclusion without considering the individual needs of each child or demonstrating its value. The other, from one of the nation's leading educators, expresses support for the effort to move ahead with inclusion. He asked to reproduce the editorial's closing admonition—"Most importantly, neither parents nor professionals should accept rhetoric in place of data."

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle # 27

SUMMER FUN at Home on your PC!

SS-ACCESS! Single Switch Interface &
DINO-GAMES Scanning Software

Available NOW from

Academic Software, Inc.

Call for free Catalog 800-842-2357

Circle # 210

DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS, continued from page 44

VIBUG BBS (Visually Impaired/Blind Users Group)
(617) 767-2909, up to 14,400 bps
Emphasis on visual impairments; conferences for parents; Fidonet; files for downloading.

MICHIGAN

Blind Ambition BBS
(313) 651-4009, up to 2,400 bps
Sponsored by Leader Dogs for the Blind, Rochester Hills, MI; emphasis on visual impairments; message areas, files/programs for blind users for downloading.

MINNESOTA

Blind Services BBS
(612) 642-0483, up to 2,400 bps
Sponsored by Minnesota Services for the Blind; some emphasis on visual impairments; Fidonet; message areas, files for downloading.

Disability Resources Affiliates & Groups Network (DRAGNET)
(612) 753-1943, up to 14,400 bps
(612) 827-2294 (voice/TTY)
Wide range of disabilities; free access, user guide available for suggested $5 donation; Internet, Fidonet, ADAnet; conferences for parents, will put other groups' newsletters online for free; many non-local callers; files for downloading.

Special Needs Network BBS
(612) 866-7371,
up to 14,400 bps
(612) 866-7380 (FAX)
General disabilities; Internet e-mail/newsgroups; inter-user chats; file areas for organizations to place their newsletters; message areas, files for downloading.

MISSOURI

Point of View
(816) 254-9116,
up to 9,600 bps
General disabilities, some emphasis on visual/hearing impairments; local issues; message areas, files for downloading.

SSMART BBS
(314) 781-6397,
up to 9,600 bps
(314) 768-5312 (voice)
Forums on brain injuries, stroke, spinal cord injuries, other disabilities; forum for parents; local issues; files for downloading.

NEW JERSEY

Disabilities Electronic Network (DEN)
(201) 342-3273, up to 14,400 bps
(201) 342-6984 (voice)
Wide range of disabilities; Fidonet, ADAnet; message areas on specific disabilities, message area for parents, files for downloading.

NEW YORK

Access BBS
(518) 885-4192, up to 16,800 bps
General disabilities; Internet e-mail, Fidonet, ADAnet, AEGIS (AIDS Education General Information Service); files specific to children with disabilities, resource info, local conferences, files for downloading.

OHIO

Disabled Individuals Movement for Equality Network (DIMENET)
(513) 439-0557, up to 14,400 bps
(513) 237-8360 (voice)
See DIMENET/Massachusetts.

OKLAHOMA

Disabled Individuals Movement for Equality Network (DIMENET)
(918) 582-3622, up to 14,400 bps
(513) 237-8360 (voice)
See DIMENET/Massachusetts.

OREGON

The DisAbility BBS
(503) 777-6561, up to 14,400 bps
General disabilities; 42 conference/ message areas—LD, ADD areas recommended for parents; Fidonet, ADAnet; files for downloading.

PENNSYLVANIA

Sounding Board BBS
(412) 621-4604, up to 14,400 bps
Emphasis on deaf-blind, visual/hearing impairments; conferences for specific disabilities; Fidonet; files for downloading.

TEXAS

CCAD Online
(214) 647-5739, up to 2,400 bps
Emphasis on assistive technology, education; BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

Microtalk BBS
(903) 832-3722, up to 2,400 bps
General disabilities, local issues, message areas, files for downloading.

Yellow Dream Machine
(512) 451-3222, up to 2,400 bps
Emphasis on disability rights, advocacy; files addressing living with a disability; most users are young adults with disabilities.

VIRGINIA

Handiline BBS
(703) 536-4182, up to 9,600 bps
General disabilities, local issues; message areas.

WEST VIRGINIA

Project Enable
(304) 759-0727, up to 9,600 bps
General disabilities; Fidonet, ADAnet; many message areas.

CANADA

ONTARIO

Abilities OnLine
(416) 650-5411, up to 14,400 bps
(416) 650-6207 (voice)
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Disability Access
(613) 837-5473, up to 9,600 bps
General disabilities; local issues; resource information.

BRITISH COLUMBIA

TASH On-Line Disability Resources
(604) 856-3661, up to 14,400 bps
(604) 856-4778 (voice)
Wide range of disabilities, health/education issues; Fidonet, Health care net, Internet; local resources; software for preschoolers/files for downloading; will provide assistance to anyone who wants to start a BBS.

ACCESSHOWER + ADJUSTEASE = CLEANING SOLUTION
IT'S SO EASY, IT'S CHILD'S PLAY!

PAT PENDING

Safe, wet fun in the shower and bath—and it goes to the beach or pool, too!
AdjustEase Washchair's your sensible back- and back-saver!

An AccessAble, successful bathtub replacement! Good-looking and barrier-free. Accesshower's an easy to do 1-day, no-plumber project!
It's a safe investment—you can even take it with you when you move!

ORDER YOUR ACCESSHOWER™ SYSTEM "CLEANING SOLUTION" BY JULY 30 TO CLEAN UP 2 MORE WAYS:
❶ SAVE 40% (up to $365!) ON YOUR CHILD'S ADJUSTEASE™ WASHCHAIR!
—PLUS—
❷ GET THE AMAZINGLY ADAPTIVE ORALGIENE™ FAMILY ORAL-CARE SYSTEM FOR ONLY $59.99! (regularly $89.99!)

AccessAble
ENVIRONMENTS + PRODUCTS FOR EVERY BODY!
1 800 285 2525
YES, WE CAN FILL 3rd PARTY PURCHASES THROUGH LOCAL DEALERS! JUST CALL US FIRST!

Circle # 9

450

Networking

Information from The National Parent Network on Disabilities

LEGISLATION

Family Support

Family support legislation is rapidly moving through both the House and the Senate. The House has attached the legislation to the Head Start legislation in Title II, "Community-Based Family Resource Programs," that passed a short time ago. Senator Tom Harkin (D–IA), chairperson of the Senate Appropriations Subcommittee on Labor, Health and Human Services; and the Senate Labor and Human Resources Subcommittee on Disability Policy, held hearings on family support and appeared likely to attach the legislation to the Individuals with Disabilities Education Act (IDEA) through a new "Part I." Even if attached to IDEA, the Department of Health & Human Services would be responsible for the administration of this legislation.

Crime Bill

Both the House and Senate have now passed their own versions of the "crime bill." NPND is working with both houses to insert language in the bill that will provide training to parents and family members to prevent children, youth and adults with disabilities from entering the criminal justice system. NPND also supports provisions for disability-sensitivity training of criminal justice professionals. Much interest in and agreement with these concepts has been expressed, but there are no assurances that the amendments NPND are seeking will become reality.

Reauthorization of IDEA

The Congress will be reauthorizing the Individuals with Disabilities Education Act (IDEA) within the next year. All signs point to this process heating up next fall with both the Senate and Administration aiming to have a bill fleshed out by November or December. Currently, the House is moving on a fast track. Representative Major Owens (D–New York) intends to have a bill completed this month. While a draft of the bill has yet to appear, staffers report that it will greatly strengthen, and more clearly enunciate the rights of parents.

The Administration is developing their bill with an expected publication of November or December. The Senate appears to be timing their activities to coincide with, or shortly follow the appearance of the Administration's bill. The House is urgently seeking input to IDEA.

NPND is seeking input now from parents across the country. We want to hear about changes that you feel are needed in IDEA. NPND also seeks stories about the positive outcomes that have been experienced by children who already are receiving their education through IDEA. We want to know what works, as well as what does not. Please forward all comments, input and anecdotes to NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, or call Larry Searcy or Patty Smith at (703) 684-6763 or (703) 836-1232 (FAX).

NPND Annual Meeting

October 1–3, 1994
Washington, DC
- **Legislation**
- **Legislators**
- **Administration Officials**

Mark your calendars now!

Goals 2000 Orientation Conference

Secretary of Education Richard Riley hosted a *Goals 2000* orientation conference May 25–27 in Washington, DC. The purpose of the conference was to assist states in designing and eventually, submitting their initial application for funds. The conference also aimed to help states launch their planning efforts under the *Goals 2000* education reform plan. Secretary Riley had asked governors and chief state school officers to send a state team, comprised of up to six members, to participate in the conference. He urged them to reach outside of state government and include team members who would reflect the full range of perspectives that will be represented on state planning panels.

ITEMS OF NOTE

Dybwad Scholarship Awards

The Rosemary F. Dybwad International Travel Scholarship Foundation has recently released guidelines to apply for one of its scholarships. The awards support travel and study abroad for anyone interested in "gaining knowledge and sharing their experiences on innovative programs that benefit persons with mental retardation." If you have interest in applying, please contact the NPND national office.

Toys "Я" Us Toy Guides

NPND, in conjunction with Toys "Я" Us, is disseminating more than 550,000 toy guides for children with disabilities. These guides contain a description of toys that classifies them by type of disability. These classifications should enable parents and other family members to better select appropriate toys for children with disabilities.

Parent Program Happenings

Patty Gerdel of *Families Together* has been successful in securing a $100,000 line item in the budget of the State of Kansas specifically to support Families Together in setting up a statewide Parent Assistance

continued on page 56

Family Support: "A Reasonable Accommodation"

Family support is a combination of assistance, services or technical supports that empower families by assuring that they can control their own lives.

On May 10, 1994, Senator Tom Harkin (D–IA) held a hearing on family support legislation. Known as *The Families of Children with Disabilities Support Act*, this legislation would allow states to receive funds under a competitive grant process to develop or enhance statewide systems of family support. The bill is not intended to provide support for direct services to families of children with disabilities. Rather, it is designed as a "systems change" bill that will assist states and families in working together to develop systems of family support that are family-centered and family-directed, and that use existing resources more efficiently. In order to receive a grant, states would have to submit an application with specific information and assurances including:

- *The designation of a lead entity in the state.* This may be an office or commission of the Governor, a public agency, an established council or another appropriate office or agency;
- *The establishment of a state Family Support Policy Council.* The majority of Council members must be family members of children with disabilities or persons with disabilities;
- *A preliminary plan*, and a description of the steps that the state will take to develop a strategic plan;
- *An assurance that families are actively involved* in all aspects of the state program; and
- *An assurance that the state will submit an annual progress report.*

This hearing was viewed by NPND as critical to the introduction and eventual passage of the bill.

The hearing consisted of testimony from five people organized into two panels. Allan Bergman, director of state-federal relations of the United Cerebral Palsy Associations, provided a concise description of the need for and benefits of family-centered, family-driven support programs. He cited family support as a "reasonable accommodation" that should be provided to families to give them a level playing field in life. Parents from Illinois, Iowa and Minnesota provided "real-life" examples of the need for effective family support programs.

Allan Bergman, of the United Cerebral Palsy Associations

Families were well represented in this hearing, and Senator Harkin appeared encouraged that the "Family Support Act" was the right policy choice, and strengthened by the packed hearing room and the support it symbolized.

Home Stretch for Health Care Reform

The President's health care reform bill got a boost recently from Senator Edward Kennedy (D–MA). The Senator, in "marking-up" the President's bill, has offered some creative and very positive alternatives. Most importantly, long-term care is very much alive in this version of the bill. Additional changes to the President's bill include: the replacement of "mandatory" alliances with "voluntary" consumer purchasing cooperatives; the opportunity for everyone to participate in the Federal Employees Health Benefits Plan if they so choose; the exemption of "mom-and-pop" businesses with five or fewer employees from the employer mandate; the basing of employer subsidies on the wages of individual employees rather than on the size and average wage of the firm; the provision of additional benefits for women, children, persons with disabilities and individuals with low incomes; the provision of increased mental health and substance abuse benefits; the creation of a new self-funded insurance program for long-term nursing home care; and an increase in support for biomedical research and academic health centers. As we go to press, the NPND Legislative Committee has not yet had the opportunity to fully review the Kennedy alternative. NPND continues its support of the President's bill. The President, it should be noted, has welcomed Senator Kennedy's mark-ups to his bill.

The National Parent Network on Disabilities Board of Directors

Richard Burden
IN*SOURCE, South Bend, IN

Joanne Butts
Washington PAVE, Tacoma, WA, *Vice President*

Amparo Crespo DeCastro
Asociacion de Padres Por Bienestar de Niños, Impedidos de PR, Inc., Rio Piedras, PR

Connie Curtin
Vermont Parent Information Center, Winooski, VT

Diana Cuthbertson
Statewide Parent Advocacy Network (SPAN), Westfield, NJ, *President*

Kathryn Erickson
Pathfinder Services of North Dakota, Minot, ND

Joe Garcia
Touchstones, Seattle, WA

Paula Goldberg
PACER Center, Minneapolis, MN

Sweet Alice Harris
Parents of Watts, Los Angeles CA

Connie Hawkins
Exceptional Children's Assistance Center (ECAC), Davidson, NC, *Past President*

Bonnie Johnson
Arkansas Parent Support and Information Network, Little Rock, AR

Joan Kilburn
MATRIX, A Parent Network & Resource Center, San Rafael, CA, *Treasurer*

Sue Pratt
CAUSE, Lansing, MI, *Vice President*

Pam Steneberg
Disability Rights Education & Defense Fund, Berkeley, CA, *Secretary*

Janet Vohs
Federation for Children with Special Needs, Boston, MA

Patricia Smith
Executive Director

Parent Program Happenings

continued from page 55

Network. For further details, contact Patty Gerdel at (913) 233-4777. Let us know what is happening with parent programs in your state—we'll share it in this column.

5 Models Available Now
The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Hedstrom Corp. of Bedford, PA

Circle # 42

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

☐ I'm interested in community involvement. Please send more information about Civitan service clubs in my community.

☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name _____

Address _____

City/State/Zip _____

Telephone Number ( ) _____

CIVITAN INTERNATIONAL, P.O. BOX 130220, BIRMINGHAM, AL 35213, **(800) CIVITAN**

Circle # 186

SAVE THESE DATES!

HEALTH PROMOTION AND COMMUNITY LIVING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

A COLLABORATIVE NATIONAL CONFERENCE

SEPT. 18-20, 1994 MADISON, WISCONSIN

HEALTH PROMOTION PROJECT

Health

FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES LIVING IN THE COMMUNITY

HOSTED BY THE HEALTH PROMOTION PROJECT
UNIVERSITY OF WISCONSIN-MADISON
520 LOWELL HALL, 610 LANGDON ST.
MADISON, WI 53703

CALL 608-265-4079 FOR MORE INFORMATION AND A FULL CONFERENCE BROCHURE.

Circle # 203

The Fun Wheeler by Roleez. (INSET) New retractable kick-stand to keep cart level and canvas sling on handle for additional leg support.

The Roleez® ALL TERRAIN *Fun Wheeler*

Our lightweight cart for children, with its amazing patented soft pneumatic wheels, is designed for ease of movement over any terrain, as easily on soft sand as on concrete. **WE GUARANTEE IT!** Disassembles easily, for storage or transporting (without tools). Great for the beach, nature trails, or just a fun ride. The addition of the Carrie® Seat by Tumble Forms® provides added support for postural control. Inquire about our Sport Wheeler for teens and adults.

1-800-369-1390

OFFICE 804-461-1122
FAX 804-461-0383

ROLEEZ WHEEL SYSTEM

5711A Sellger Drive, Dept. E, Norfolk, VA 23502

Reprinted by permission of J.A. Preston Corporation 1990 Bissell Healthcare Corporation

Circle # 201

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- *Physical Therapy*
- *Occupational Therapy*
- *Speech and Language Therapy*
- *Communication Aids*
- *Special Education*
- *Music Therapy*
- *Special Medical Attention*
- *Adapted Recreational Activities*

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
	Apple Computer	26
210	Academic Software	53
9	Accessable Environments	54
170	Aquatic Therapy	62
6	Berkshire Meadows	7
7	BHC-JA Preston	C4
90	Chrysler	19
185	Children's Specialized Hospital	38
186	Civitan International	57
11	Columbia Medical	33
13	Columbia Medical	41
109	Consumer Care	40
14	Crow River	49
18	Cumberland Hospital	25
19	Devereux	52
25	Equipment Shop	36
26	Estate Planning	24
	Exceptional Parent Library	66, 67
27	Evergreen	53
29	Flaghouse	29
30	Ford	13
34	GMR Labs	11
199	Hacienda de los Angeles	62
39	HMS School	58
36	Haverich Ortho-Sport, Inc.	6
38	Heartspring	64
121	IBM (Special Needs Systems)	14
41	Imaginart	40
42	Innovative Products	57
147	Kimberly Clark	5
200	League School of Boston	62
46	Kid-Kart	15
48	Laureate Learning	C3
15	Marblesoft	62
169	Milani Foods	17
92	Quickie Designs	34, 35
66	Rifton	44
201	Roleez Wheel System	58
75	St. John's Villa	46
202	Temasek Telephone	46
68	Sentient Systems	3
122	TMI	14
178	TMI	46
203	University of Wisconsin	57
85	Voorhees Pediatric	36
86	Woodbury Products	24

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month
17❑ three months
18❑ nine months
19❑ one year

Issue Date: June 30, 1994

Expiration Date: September 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month
17❑ three months
18❑ nine months
19❑ one year

Issue Date: June 30, 1994

Expiration Date: September 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

Market Place

Augmentive Communications

Consultants for Communication Technology
508 Bellevue Terrace
Pittsburgh, PA 15202
(412) 761-6062
CCT manufactures hardware/software products for AAC systems and phone access for the speech & hearing impaired. Products include the Handy Speech Communication Aide, Wish Writer, Phone Manager, Tonetalk, META4, and other state of the art products at reasonable prices.

Bibs

Ross' Bibs
Haco, Inc.
PO Box 5642, Asheville, NC 28813
(704) 274-0075
These Bibs were originally made for our son, Ross, by his Aunt Catherine. Now we can make them for your special child. They are made of machine washable, long lasting, heavy duty vinyl. The large child size is $13.95. The teenage/small adult size is $15.95; plus $2.00 shipping. Other sizes available, please call for more information.

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No online charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Computer Software

Judy Lynn Software
278 Dunhams Corner Road
East Brunswick, NJ 08816
(908) 390-8845
IBM PC single switch software. Cognitive age level from 9 months. Programs range from $20 – $35. Switch adapter $23. Free catalog.

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical
$100 Off Car Seats. Equipment and Supplies Discounted to 50%. Call 800-877-9100. Free brochure.

New York

Dowd Medical
1010 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been serving the area since 1930. For personal service and quality equipment call Dowd.

Rehabco
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in children's mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96). Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Mobility

Blue Sky Cycle Carts
PO Box 5788
Bend, OR 97708
(503) 383-7109
Enjoy cycling with the whole family. We offer customized bicycle trailers adapted to carry children & adults with special needs.

Books, Audio/Video & Educational Material

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

"Little Bits of Rainbow"
12 original songs in the Judy Collins tradition, for parents of children with special needs. By Marianne Kallen. Cassette only, $11.95, P.O. Box 1393, Highland Park, IL 60035

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Publications

Hydrocephalus News/Notes
Published quarterly for affected individuals/ families & professionals who specialize in their care. Highlights: medical/technical articles, human interest stories, great resources! A. Liakos, Editor, HNN, 1670 Green Oak Circle, Lawrenceville, GA 30243. $25 year.

Obviously, a computer program can't take the place of a good teacher. But the Early Learning series from Marblesoft is a tool that helps teachers keep learning fun for early elementary and special education students.

The software is easy to use -- for both the student and the teacher. And when used with a speech synthesizer, there's the added advantage of a human-sounding voice that praises right answers and gently encourages the student after wrong ones.

For more information and a complete product catalog, please call (612) 755-1402.

MARBLESOFT

12301 Central Ave. N.E. Blaine, MN 55434

Circle # 15

Home Away From Home

Quality care in a state-of-the-art medically oriented, yet home-like, facility for chronically ill infants, children, and young adults. A one of a kind program staffed by doctors, nurses, therapists, and teachers. If you are thinking about having your loved one cared for outside your home, consider Hacienda de los Angeles with 26 years of experience helping families and their chronically ill family members. Hacienda is located in a semi-rural setting bordered by beautiful South Mountain Park, yet is less than five minutes from the Owens Medical Center.

Hacienda's comprehensive program offers:

- Specialized care for individuals with tracheostomies and those who are ventilator dependent.
- A new facility staffed by professional yet caring employees.
- Open door 24-hour visitation.
- Physician services and round-the-clock nursing care.
- Twenty-four hour respiratory therapy.
- In-house physical, occupational, and speech therapy.
- Nutritional services by a certified nutritionist.
- On-grounds and public school based educational services.
- Private and semi-private rooms.
- Individualized programming designed to allow your family member to reach his/her full potential.
- In-house specialized equipment construction and equipment adaptation.
- Transportation in specially equipped vehicles.

Hacienda de los Angeles, Inc.

In Special Lives, We Make A Difference
1402 East South Mountain, Phoenix, AZ 85040
(602) 243-4231
William J. Timmons, Executive Director

Circle # 199

Providing Quality Services for Children and Adults with Autism and Related Developmental Disabilities

LEAGUE SCHOOL OF BOSTON

Day	Residential	Farmstead
Early Intervention - Age 22	Ages 6-22	Age 18 - Adulthood

Twelve-Month Day Educational Programming

Specialized Community Residences

Early Intervention and Home Training

Community-Based Supportive Employment and Vocational Training

After-School Recreational Programs

Friendship Farms: Adult Farm Living in the Heart of Cranberry Country

League School of Boston, Inc.
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260

Herman T. Fishbein
Executive Director

Accreditation: Massachusetts Dept. of Education, Office for Children, Dept. of Social Services, Dept. of Mental Retardation, Dept. of Mental Health, NY Dept. of Education

Circle # 200

* Improves coordination, postural control and muscle tone.
* Provides independence.
* Secured in center with belt or seat.
* Trade-in policy.
* S.M.L
* Covered by most insurance companies.

THE WATER WALKER

* Prone or supine support.
* Contour lines that allow use of arms and legs.
* Straps to secure person on float.
* Pillow for head support.
* S.M.L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

VISA MasterCard

Circle # 170

WHAT'S HAPPENING

Career Planning for People with Visual Impairments

The American Foundation for the Blind operates the *Careers and Technology Information Bank*, a network of 1,600 people with visual impairments who use a wide range of assistive technology equipment in a variety of careers. Established in 1968, the bank includes a database of information based on interviews with each member. Bank users can talk with members about career planning and assistive technology issues; parents or teachers can use the bank to find a role model with a visual impairment for their children or students. Contact *Careers and Technology Information Bank*, American Foundation for the Blind, 15 W. 16th St., New York, NY 10011, (212) 620-2080.

Call NICHCY Toll-Free!

The National Information Center for Children & Youth with Disabilities (NICHCY) has a new toll-free number—(800) 695-0285. If you have questions about disability issues pertaining to children and youth, NICHCY staff can provide answers, referrals to experts in the appropriate field and free printed information in English or Spanish. NICHCY can also provide technical assistance to other information providers. NICHCY, P.O. Box 1492, Washington, DC 20013.

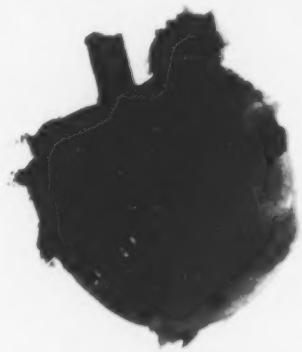
PUBLICATIONS

• A national directory of local hydrocephalus support groups is available. Cost is $1.50, available from Hydrocephalus Association, 870 Market St., San Francisco, CA 94102, (415) 776-4713.

• *Swallowing Problems: A Caregiver's Manual* provides guidance to family members and caregivers on how to identify swallowing problems, get help and implement a treatment plan. This free brochure is available from the American Speech-Language-Hearing Association (ASHA), 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY).

• Also available from ASHA is a free, 18-page information packet on cochlear implants. The packet provides practical information on the types of cochlear implants, who is a suitable candidate, what to expect from the evaluation process and an extensive list of resources for further information. Contact ASHA, 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY).

• *Living Your Own Life* is a handbook for teenagers written by young adults with disabilities or chronic illnesses. The authors share their views and experiences on managing their lives. The handbook costs $8.00. A companion volume, the *Speak Up for Health Parent Handbook*, helps parents prepare adolescents with disabilities for self-advocacy. The handbook, which costs $10.00, discusses letting go, health insurance, sexuality and other issues. Available from PACER Center, 4826 Chicago Ave., S., Minneapolis, MN 55417-1098, (612) 827-2966 (V/TTY).



"Apple," by K.C. Ruback, Omaha, NE

• The American Brain Tumor Association provides a number of free publications for families and friends of individuals with brain tumors. Their newest publication is *Alex's Journey: The Story of a Child With a Brain Tumor*, a book for children ages 9-13. Contact American Brain Tumor Association, 2720 River Rd., Des Plaines, IL 60018, (800) 886-2282.

• *Wide Smiles* is a quarterly publication that addresses the needs of families of children born with cleft lip and palate. Subscriptions are $18/year or $34/two years. Contact *Wide Smiles*, P.O. Box 5153, Stockton, CA 95205-0153, (209) 942-2812.

• The National Tay-Sachs & Allied Diseases Association has recently published *The Home Care Book*, a guide written by and for parents caring for children with progressive neurological diseases. Contact NTSAD, 2001 Beacon St., Suite 204, Brookline, MA 02146, (617) 277-4463. Cost is $3.00 including postage/handling.

• *A Heartbreaking Choice* is a quarterly newsletter for parents who have interrupted a pregnancy after a prenatal diagnosis of fetal anomalies. Each issue contains articles written by parents who have faced this difficult decision, information from professionals and helpful resources. Subscriptions are $15/year for parents and $25/year for professionals. For subscriptions or a complementary issue, contact Pineapple Press, P.O. Box 56, Mullet Lake, MI 49761.

• The Child Care Careers Institute has published a handbook, *Integrating Children With Special Needs Into Pre-School Settings: A Resource Handbook*. Though written primarily for child care professionals, the guide also features many helpful resources for families—books for children and adults, clearinghouses, organizations, publications and videos that address special needs issues. Contact Child Care Careers Institute, 99 Bishop Richard Allen Drive, Cambridge, MA 02139. $5.00 including postage/handling.

• *Hydrocephalus News & Notes* is a quarterly publication for children and adults affected by hydrocephalus, their families and professionals. The newsletter provides resources, research and parent networking information for families with children who have hydrocephalus associated with spina bifida, Arnold-Chiari malformation, holoprosencephaly, lissencephaly, micro- and/or macroencephaly, Sturge-Weber syndrome, neurofibromatosis, porencephalic cysts, Dandy-Walker syndrome, encephalocele and agenesis of the corpus callosum. Subscriptions are $25/year. For subscriptions or a complementary issue, contact Ann Marie Liakos, *Hydrocephalus News & Notes*, 1670 Green Oak Circle, Lawrenceville, GA 30243, (404) 995-7334.

459

"It's your turn, David." "What's the matter?" "Do you want pizza or a hamburger for lunch?"

Answering questions, making choices, and expressing emotions are everyday occurrences for you and me. But for David, they create a world of challenges, confusion, and frustration. David is non-verbal.

David came to Heartspring with a limited signing vocabulary, and because of his restricted motor skills, even those words were hard for others to understand. Today, he is able to tell you he doesn't want to play that game right now, or he has decided on pizza for lunch. He does this through the use of various alternative communication systems. His vocabulary and independence constantly increase.

Heartspring's speech therapists tailor the systems to meet the needs of each child. A child may start out with picture boards and books, and then may combine them with a system using single words then phrases. Sometimes an electronic communication device, which is set up with pre-recorded words matching the picture or word pages, is used by a child.

The door of communication is open for David and many other children at Heartspring with the use of various alternative communication systems and the skills and encouraging words of caring, trained professionals.

If your child – or a child you know – needs help unlocking that door, call Heartspring today.

HEARTSPRING℠
A LIFESKILLS LEARNING CENTER
2400 JARDINE DRIVE · WICHITA · KANSAS 67219-4699
1 · 800 · 835 · 1043

Formerly the Institute of Logopedics
1934 – Celebrating 60 Years Of Service – 1994

EXCEPTIONAL PARENT
Parenting Your Child With a Disability

120 State Street
Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)
Fax (201) 489-1240

Vice President Advertising Sales
KERRY J. CANNON

Sales Representatives

BARBARA NASTRO
New England, East Canada,
DE, DC, MD, NJ, NY, PA, VA, WV
Schools, Camps, Residences, Classified & Special Sales
(201) 680-4874
(201) 680-8355 Fax

WILLIAM MIDDLETON
Southeast (AL, FL, GA, KY, MS, NC, SC, TN)
(404) 973-9190
(404) 565-7013 Fax

ANTHONY ARNONE
Midwest (IN, KS, MN, ND, OH, SD, UT, CO)
(708) 428-5162 Phone and Fax

JOHN MAISEL
Midwest (IL, IA, NB, MI, MO)
(708) 416-0780
(708) 416-0793 Fax

JANE HAYWARD
Southwest (AR, AZ, LA, NM, OK, TX)
(714) 366-8455
(714) 366-9289 Fax

RICHARD AYER
West Coast (So CA, NV)
(714) 366-9089
(714) 366-9289 Fax

WILLIAM HAGUE
West Coast (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
(206) 858-7575
(206) 858-7576 Fax

Ad Traffic Manager
STEFANIE FERRANTE
120 State Street
Hackensack, NJ 07601
Phone (800) E-PARENT (372-7368)
Fax (201) 489-1240

BPA International Consumer Magazine
Membership Applied for August 1993.

NEW PRODUCTS

VERSA FORM™ BY TUMBLE FORMS

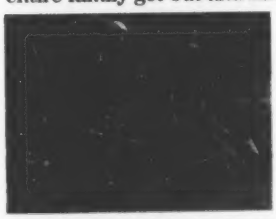
Finally, a reusable positioning aid that is cost-effective and versatile! The Versa Form is a styrene-bead-filled vinyl pillow that holds a child's form for up to 24 hours when vacuum pressure is applied. By allowing air to enter the pillow, it becomes supple again and may be reformed for any child, in any position, as many times as needed. For sitting, side-lying, prone or supine positions and for specific extremity or joint stabilization, the Versa Form will accommodate many needs easily.

J.A. Preston Corp., Jackson, MI 49204-0089.

Circle # 204

THE DUET™

This cycle-and-wheelchair combination unit will help the entire family get out and have fun! Together, the unit is a three-wheeled cycle allowing the passenger to enjoy the sensations of cycling. At a rest stop or park, a quick-release mechanism disengages the passenger seat, which becomes an independently- functional wheelchair—no transferring or transporting an extra wheelchair! Meets safety standards. Optional positioning accessories are available.

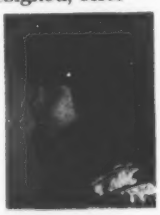


TechnoMarketing, Inc., Rougemont, NC 27572.

Circle # 205

ANTERIOR HEAD SUPPORT

The Anterior Head Support has been redesigned, offering a closed front and reinforced sides to allow firm but gentle lifting of the chin and lateral support for the head. This device, designed for individuals who need supplemental support, does not attach or mount to a seat or headrest. The support, made of vinyl-covered foam, covers the entire neck area and is secured in the back. A soft, comfortable terry cloth cover is included.

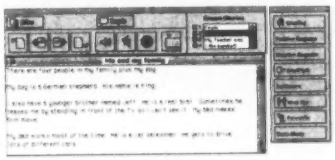


Danmar Products, Inc., Ann Arbor, MI 48103.

Circle # 206

TALK:ABOUT™

This conversation software for augmentative and alternative communication is designed for use on Macintosh computers. It allows fast social interaction and wants-and-needs communication. The software includes "Starters," programmed small-talk phrases; "Wrap-ups and Farewells," preprogrammed to gracefully end a conversation and say good-bye; the ability to create novel sentences and to extend talk with Co:Writer and a "QuickChat" button for instant communication. The software is menu-driven with intelligent icons, allowing the user to move from one stage of a conversation to another quickly and easily.

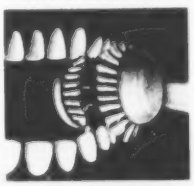


Don Johnston, Inc., Wauconda, IL 60084-0639.

Circle # 207

ORALGIENE™

A device to help parents brush their child's teeth or to allow a child to brush independently, the Oralgiene is a battery-powered toothbrush with bristles automatically positioned at the correct angle prescribed by dentists. The user bites lightly into the brush head, and the bristles rotate to clean six tooth surfaces at the same time. The handle is much wider and thicker than conventional toothbrushes, diminishing the need for manual dexterity.

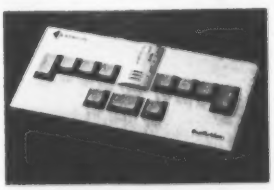


Oralgiene USA, Inc., Los Angeles, CA 90024.

Circle # 208

SPANISH BRAILLEMATE

This pocket-sized, electronic Braille notetaker is now available in the Spanish language. Students can write, proof and edit in grade-1 or grade-2 Braille, then print on an inkjet printer. Newly developed speech synthesizer provides high-quality speech output in Spanish for all of BrailleMate's functions—notebook, clock, calculator, calendar and address/phone book.



TeleSensory Corp., Mountain View, CA 94039

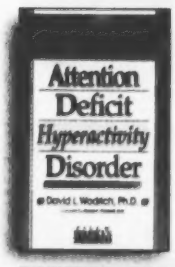
Circle # 209

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

461

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER



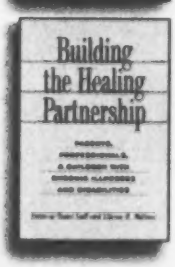
ATTENTION DEFICIT HYPERACTIVITY DISORDER: ***What Every Parent Wants to Know***
D. WODRICH
Prepares parents for at home and at school, empowers and reaffirms parents of their role.
PB070AD **$19.95**

AUTISM

REACHING THE AUTISTIC CHILD
MARTIN KOZLOFF
Focuses on a parent training program that shows how to improve the environment of the autistic child.
BL0630D **$14.95**

DISABILITY, GENERAL

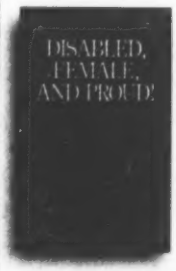
BROTHERS AND SISTERS
A Special Part of Exceptional Families
THOMAS H. POWELL
Includes 30 parental strategies and 20 sibling strategies suggested by a panel of siblings.
PB072OD **$23.00**



BUILDING THE HEALING PARTNERSHIP: ***Parents, Professionals & Children with Chronic Illnesses and Disabilities***
PATRICIA T. LEFF
BL057OD cloth: $34.95 paperback: $24.95

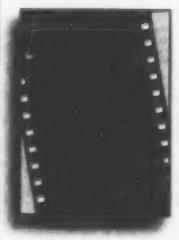
CHILDREN WITH DISABILITIES: ***A Medical Primer***
M. BATSHAW
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.
PB071OD **$29.00**

DECIPHERING THE SYSTEM: ***A Guide for Families of Young Children with Disabilities***
PAULA J. BECKMAN
Informs parents of children (0–5) of their rights.
BL058OD **$21.95**



DISABLED, FEMALE, AND PROUD! ***Stories of Ten Women with Disabilities***
HARILYN ROUSSO
Offers young women with disabilities empowering role models.
GW003EP **$12.95**

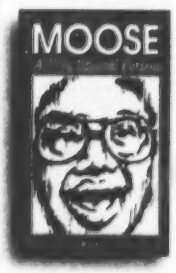
THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services.***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**



THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR! ***Siblings of Children with Disabilities***
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals
EP001EP **$14.95**

LIVING IN THE STATE OF STUCK: ***How Adaptive Technologies Affect the Lives of People with Disabilities***
MARCIA J. SCHERER
BL064OD **$32.95**



MOOSE: ***A Very Special Person***
W. SCOTT MACDONALD
Moose teaches us that each of us is different and that we have our own unique capacity for loving, sharing, enjoying and learning.
BL065OD **$10.95**

PERSPECTIVES ON A PARENT MOVEMENT: ***The Revolt of Parents of Children with Intellectual Limitations***
ROSEMARY DYBWAD
Captures the author's truly innovative wisdom and pioneering work.
BL059OD **$17.95**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

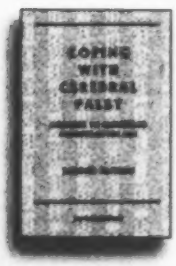
PLANNING FOR THE FUTURE: ***Providing a Meaningful Life for a Child with a Disability after Your Death***
MARK RUSSELL
AP024OD **$24.95**

THIRD PARTY BILLING FOR SPECIAL EDUCATION: ***Panacea or Mirage?***
JOY J. ROGERS
The use of third party billing to cope with escalating special education costs, especially those not directly educational.
BL066OD **$27.95**

THE TRAVELIN' TALK DIRECTORY: ***When the Traveler Has a Disability***
RICK CROWDER
The ultimate directory of resources providing assistance to travelers with disabilities. Information is gathered from hundreds of members nationwide.
RC076OD **$47.50**

WINGS TO FLY
Bringing Theatre Arts to Students with Special Needs
SALLY DOROTHY BAILEY
A comprehensive nuts & bolts handbook for special education and drama teachers at the elementary & high school levels.
WB075OD **$17.95**

DISABILITY, PHYSICAL



COPING WITH CEREBRAL PALSY: ***Answers to Questions Parents Often Ask***
JAY SCHLIECHKORN
Provides answers to more than 300 questions that have been carefully researched.
PE037PD **$24.00**

I WISH...
Dreams & Realities of Parenting a Special Needs Child
KATE DIVINE MCANANEY
A book about conflict, courage and creative solutions.
CP074CP **$8.95**

NO TIME FOR JELLO
One Family's Experience with the Doman-Delacato Patterning Program.
BERNEEN BRATT
One family's experience with patterning for a child with Cerebral Palsy.
BL062CP **$17.95**

TAKING CHARGE:
Teenagers Talk About Life & Physical Disabilities
EDITED BY K.H. KRIEGSMAN
Explore the wide range of issues that teenagers with physical disabilities face as they approach adulthood.
WB013PD **$14.95**

INJURY

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$5.00**

WHEN YOUR CHILD IS SERIOUSLY INJURED:
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$2.00**

MENTAL RETARDATION

COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME
A Guide for Parents
LIBBY KUMIN
Parents learn how communication skills progress from infancy through the early teenage years.
WB031DS **$14.95**

COUNT US IN
Growing Up with Down Syndrome
J. KINGSLEY & M. LEVITZ
The authors share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship.
HB073DS **$9.95**

DEATH AND DYING:
A Guide to Serving Adults with Mental Retardation
M. HOWELL
Explores psychological, medical, spiritual and legal matters.
GW004EP **$7.95**

DOWN SYNDROME:
An Introduction
CLIFF CUNNINGHAM
A comprehensive and well organized work for parents of babies and children. Answers to countless questions.
BL068DS **$12.95**

ETHICAL DILEMMAS IN CAREGIVING: ***A Guide for Staff Serving Adults with Mental Retardation***
M. HOWELL
Examines cases where there are clear-cut dilemmas about the "best" course of action.
GW069MR **$8.95**

SERVING THE UNDERSERVED:
A Handbook for Caregivers
EDITED BY D. GAVIN
All the areas of experience affecting the lives of adults who are mentally retarded and old.
GW011MR **$29.95**

Mail to: **Exceptional Parent,** Dept. EP9406, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date ____/____

Signature _____

CHILDREN'S PAGE

REMEMBERING DANIEL

by Nathan Reiff

I once had a brother. His name was Daniel Jordan Reiff. He died at age five and a half. He had pyruvate dehydrogenase deficiency. He was my absolute best friend.

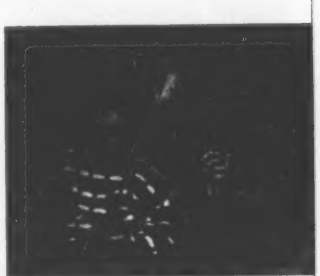
When Daniel was two years old, he could say 50 words. Then, he got sick and lost all his words except for "Naa Naa" (his name for me), "Mama" and "Daddy." He crawled a lot—so much that my little sister called him a "crawl boy." I loved him a lot, even though he had a disability. Sometimes, I felt lonely because none of my friends had brothers like Daniel. He was really, really hard to take care of and it took a lot of time, but I still loved him.

Nathan is nine years old. He is in third grade at Edgewood Elementary School in Eugene, Oregon. Nathan lives with his mother, Ginny; his father, Bud and his three-year-old sister, Rachel. His hobbies are soccer, drama, math and reading.

Nathan and his family will always miss Daniel, but they have many precious and happy memories that help them get through tough days. They are building a memorial garden for Daniel. This year, they planted two lilac bushes in the garden.

After school one day, when Daniel was in the hospital with mononucleosis, my friend's mom came and took me to the hospital. Then, my mom told me to say good-bye to Daniel because he wasn't going to make it through this hospital stay. I said good-bye and I kissed him. At 7:20 p.m., on May 3, 1993, he died. I knew this was going to happen, but I was not ready for it. I was at my aunt's and uncle's house when he died.

Daniel's funeral was on May 8. It was my idea to put lilacs in his casket because they were just blooming. I also put in a note that said how much I loved him and missed him. I was not only sad; I also was angry.



That was one long year ago. Back then, many changes were arising. We lost Daniel, and we moved from Lynnwood, Washington to Eugene, Oregon. We did not have friends or relatives in Eugene. It was a hard time for me.

Now, I am doing better. I have some good friends, and I'm seeing a counselor. I still feel a little bit of regret about moving. I mean, there's only so much an eight-year-old can handle at one time!

Even with all of those things helping me, I still am not totally okay about Daniel dying. As I said before, he was my absolute best friend. I will never have a best friend exactly like him again. I *really* miss you, Daniel.

Spectacular Summer Software Sale

50% OFF all Laureate software

From Words & Concepts

For over ten years, Laureate has been producing programs to meet the unique needs of exceptional children. We want your child to benefit from using our award-winning software at home. That's why we're reaching out to parents with this *Spectacular Summer Software Sale*.

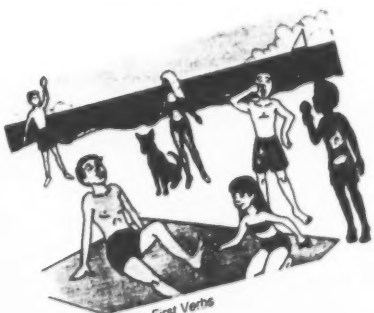
From now until August 31, 1994, you can purchase Laureate's talking software programs for an incredible 50% off. We'll even pick up the shipping charges! Your satisfaction is guaranteed. If our software doesn't meet your child's needs, for whatever reason, we'll take it back.

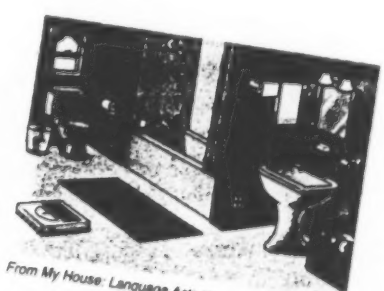
Available for Apple II, Apple IIGS, IBM, and Macintosh computers

Call today for a free catalog.

1-800-562-6801

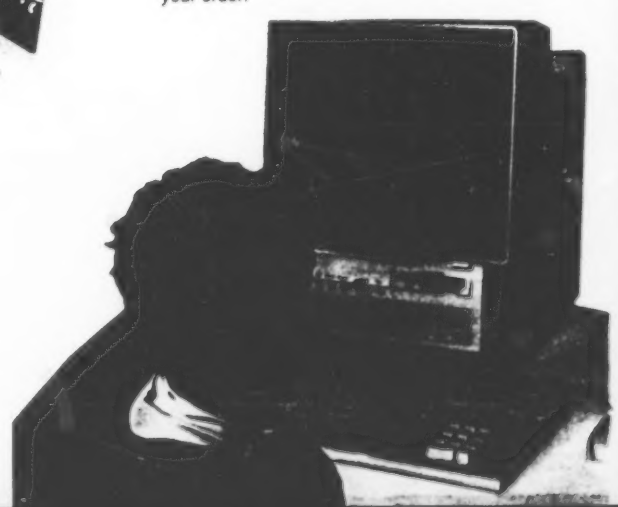
This offer applies to individuals only. No school, agency, or institutional purchase orders, please. We will accept orders prepaid by check, MasterCard, or VISA. Free shipping within the U.S. only. Please mention this sale when placing your order.


From Exploring First Verbs


From My House: Language Activities of Daily Living

We have over 60 talking software programs for children functioning between 6 months and 8 years of age.

- **Language intervention**
- **Cognitive processing**
- **Reading**
- **Instructional games**



465

Laureate

Circle # 48

Laureate • 110 East Spring Street • Winooski, VT 05404 • 802-655-4755

Tri-Angles

Three angles, three times the therapy - the new TriStander® 58 positioning stander from Tumble Forms®.

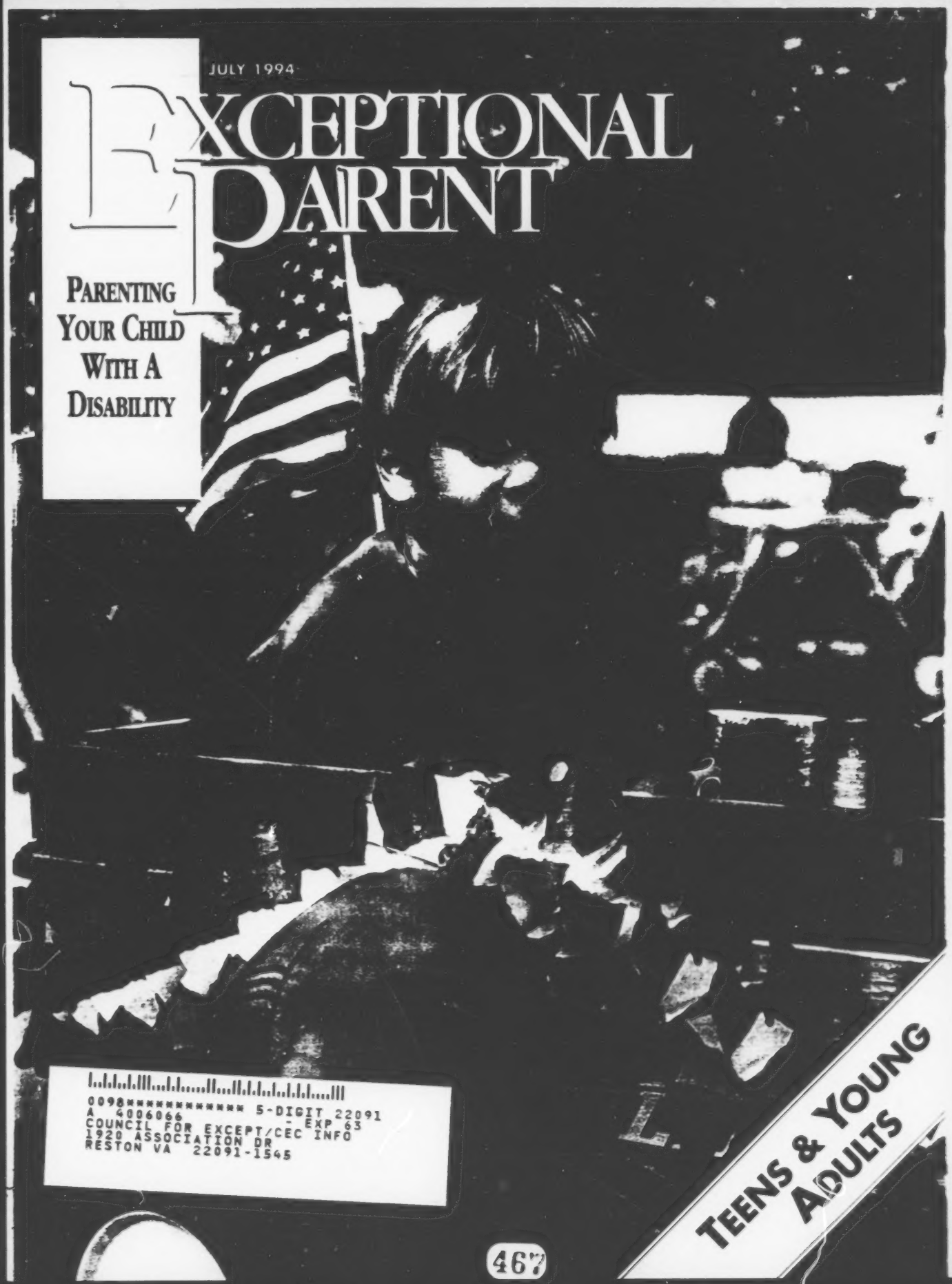
Like the original TriStander 45, the new TriStander 58 is actually three standers in one. A unique design allows infinite adjustments between vertical, prone and supine so you need only to invest in one stander to meet all of your positioning needs. The frame is adjustable for height and what's more, the module support components come in a variety of sizes and can be ordered separately allowing you to adapt the stander to your client's individual size and shape. The new TriStander 58 accommodates individuals from 45 to 58 inches tall; TriStander 45 accommodates those 32 to 45 inches.

Three angles, one stander, unlimited use. For more information call 1-800-631-7277. In Canada, call 1-800-665-9200.

Tumble Forms® tristander® 58

by **Preston**

Circle # 7



0098********** 5-DIGIT 22091
A 4006066 EXP 63
COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1545

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING
PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day maximum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford and Lincoln-Mercury Division

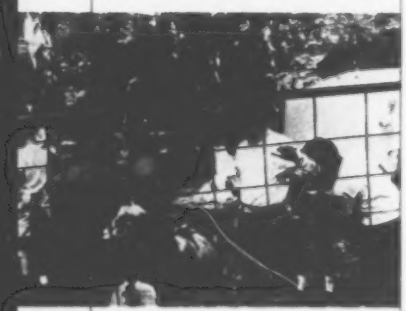
Circle # 30

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

JULY 1994
VOL. 24, ISSUE 7

COVER:
Four-year-old Philip Gibbons celebrates the Fourth of July by joining a children's parade that has become an annual tradition in his neighborhood. Philip, who has autism, lives in Chevy Chase, Maryland.



PAGE 36

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved, Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE**: Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries*: No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

FEATURES

The Dangerous Yew by Sally Caroline 20
Sword fights with bushes and other tales of growing up with blindness.

A Date to Remember by John Gray 24
A young man's dream date turns into a nightmare.

The First Time by Robert Perretz-Rosales 31
A father reacts to his son's first seizure.

All Children Belong 36
A national program to promote inclusion.

DEPARTMENTS

Editor's Desk 2

Search & Respond 4

Letters 12

Health Insurance Troubleshooter 16
Richard Epstein tackles health insurance quandaries.

Role Models: JOHN KEMP 34
UCPA executive director talks about growing up with inclusion.

Fathers' Voices: NOT FOR A NICKEL AND A DIME by David M. Cameron 42
Will's father declines a "handicapped discount" for his son's carousel ride.

Media: HONOR THY SON by Lou Shaw 44
An adventure novel that turned into a love story.

Point of View: DISABILITY REALLY ISN'T THAT ROMANTIC by Elaine Greenbaum 46
Work disincentives for persons with disabilities.

Ask the Doctor 50
Dr. David Hirsch answers commonly-asked questions about incontinence.

Youth Connections 53

Directory of Advertisers 58

What's Happening 63

New Products 65

Familiar Faces 66

Children's Page 68

EDITOR'S DESK

Teenagers and Young Adults

When girls and boys become teenagers and young adults—whether or not these children have disabilities—their mothers and fathers also find themselves in a new phase of their development as parents. Parents realize that they are no longer young adults themselves. This may be part of the reason that many parents wish they could skip this phase in everyone's development and magically catapult their offspring from elementary school to independent adulthood.

STANLEY KLEIN, PH.D.

In current discussions of teenagers and young adults, the word "transition" comes up frequently. People talk about transitions from school to work, from home to away-from-home, from short-term social relationships to long-term commitments, from relative dependence to relative independence, from family member to family creator. Parents may also face transitions of their own as they deal with the challenges of caring for their own parents or older relatives.

For teenagers and young adults with disabilities and their parents, these transitions involve charting new territory. Because societal attitudes and opportunities are evolving rapidly, we have neither a long history from which to learn nor many experts upon whom we can call.

In this issue, three features—John Gray, *A Date to Remember*; John Kemp, *Role Models*; and a young adult panel discussion, *Living the Course*, included in *Youth Connections*—deal with social relationships. *Charting the Course*, also in *Youth Connections*, deals with the emotional aspects of transitions from youth to adulthood.

Despite many positive attitude changes, uncertainty about the future remains. This is especially true, as Elaine Greenbaum describes in *Point of View*, when young adults with disabilities who want to work face the peculiar disincentives that appear to be built into the system. Clearly, more changes are needed.

New Departments

Because our readers have many concerns about health care and about health insurance, this issue has the first installments of two new, regular departments on these topics. Both will respond to readers' questions.

- In *Ask the Doctor*, David Hirsch, M.D., a member of our Editorial Advisory Board, answers commonly-asked questions about toilet training and incontinence. In future issues, Dr. Hirsch will respond to selected readers' questions as well as invite the participation of other experts.
- *Health Insurance Troubleshooter* is a role that Richard Epstein assumed when he became a person with a disability. In his first article, he describes some of the complexities of dealing with health insurance companies and ways that parents can cope. Like Dr. Hirsch, Mr. Epstein encourages readers to write to him with their health insurance questions and quandaries.

Send questions for Dr. Hirsch or Mr. Epstein to *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005. Or fax questions to 617-730-8742.

Fathers

This issue includes another wonderful Fathers' Voices article, *Not For a Nickel and a Dime*, by Will Cameron. It also includes *The First Time*, a poignant story by another father, Robert Perretz-Rosales, about a child's first seizure. Last but not least, Lou Shaw, another father featured in this issue, has just written a fascinating adventure novel about a young man with a disability who is accused of murder.

Inclusion

All Children Belong is the first of a series of articles describing an exciting national project to promote the inclusion of children with disabilities in their local schools and communities. In September, our 22nd annual education issue will discuss inclusion from a variety of perspectives.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology, New England College of Optometry

ASSISTANT EDITOR Kim Schive

EDITORIAL STAFF Valerie Steele

EDITORIAL INTERNS
Simone Albeck, Katie Beckett, Jennifer Fisher, Ludmilla Panza, Sara Wood, Pyongson Yim

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 FAX (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Sutera

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferranté

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (IN, KS, MN, ND, No OH, SD, UT, CE))
Anthony Arnone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, NB, MI, MO, So OH)
John Maisel
(708) 416-0780 Fax (708) 416-0793

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
William Hague
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESIDENCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58. BPA International Consumer Magazine Membership Applied for August 1993.

470

A scientific breakthrough in dental hygiene

THE AUTOMATIC TOOTHBRUSH

THE AUTOMATIC TOOTHBRUSH

Dental professionals agree that the key to cleaner teeth and healthier gums is in the brushing technique. That is why the Oralgiene Automatic Toothbrush is designed to position its bristles under the gumline at the exact angle dentists prescribe, everytime you brush.

Reaching all tooth surfaces and below the gumline in one easy action, Oralgiene™ thoroughly cleans your teeth while massaging under the gum line in just 60 seconds.

Because Oralgiene™ requires no knowledge of proper brushing technique or skill, it's almost impossible to use wrong and it's incredibly easy to use for both adults, children and care givers.

With research proven effectiveness the ADA accepted Oralgiene™ will give you and your family clean healthy teeth and gums, fresh breath and a winning smile.

Oralgiene™ unit includes 2 color coded brush heads, battery pack, plug-in recharger and storage stand. A one year warranty and a 30 day money back guarantee.

OFFER: Oralgiene™ $79.95 plus $5.00 shipping and handling.

Call toll free to order
1-800-933-ORAL (6725)
VISA, MC, DISCOVER, AMEX, or send check or money order to:

Oralgiene USA, Inc.
421 North Rodeo Drive, Suite 15114
Beverly Hills, CA 90210

CA & NY Residents add 8.25% sales tax.

ORALGIENE

The Science of Oral Hygiene

Circle # 219

SEARCH

Episodes of Increased Activity

My 11-year-old son has agenesis of the corpus callosum with resulting athetoid cerebral palsy and moderate mental retardation. He also has periodic episodes of highly increased motor activity, elevated heart rate, dilated pupils, abnormal respiration and increased muscle tone. His EEG is normal; blood and urine tests reveal nothing. I would like to correspond with anyone who has any information concerning these episodes.

P.B., Oklahoma

Severe Shaking

I am the mother of a five-year-old girl who has ataxic cerebral palsy. Annie cannot walk unassisted, but uses a walker with supervision. Her main form of mobility is to bunny-hop everywhere.

Over the past year, Annie has developed a very severe shaking pattern that paralyzes her movements for a few minutes. Her whole body goes rigid and she shakes violently. It is not a seizure. She is aware of what is happening and will usually start to whimper as if frightened. She can make the shaking stop if you put her on the floor and let her hop very hard and fast. Sometimes the shaking starts when she is already hopping. When this happens, she becomes rigid and cannot move—almost as if she is stuck. In these cases, she usually throws herself down on the floor and rides it out. These episodes usually last several minutes; then, she is perfectly fine and goes back to her normal movement patterns.

Some clear triggers of these episodes are loud noises, being spoken to in a reprimanding tone of voice and fear of people or places. But the shaking also happens when she is perfectly relaxed and calm. Now, these episodes are becoming more frequent and interfering with daily life. They happen at school, at meal times, when walking or using the potty--just about any activity can be interrupted by a shaking spell.

The neurologists don't know what is causing these shaking spells. Annie has been tested and does not have a degenerative disease. Does anybody out there know what's going on with my child? If you have a child like Annie, please write to me!

S.W., Georgia

Partial Trisomy Eight

I am looking for another parent of a child with partial trisomy eight. My daughter is 16 years old. I'd love to hear from parents who could help me know more about her future.

E.F., Colorado

Darrow Syndrome

We have a 19-month-old daughter with Darrow syndrome—also called chloride-diarrhea. We have heard of only 14 cases of this in the U.S. and would like to contact other parents of children with this genetic disorder.

T.W., Ohio

Angelman Syndrome

My son, Christopher, is three years old. At age two, he started having drop attack seizures and was diagnosed with Angelman syndrome (AS). Chris is on medication to control his seizures. He is a very active child who needs one-on-one supervision at all times.

Christopher's doctors have told me that they do not know of another black child with AS. I don't know what Chris will learn to do next or what medical problem may arise. I would like to contact other parents of children with AS. I have a lot of questions.

V.R., Ohio

EDITOR'S NOTE: You can contact the Angelman Syndrome Foundation at 5950-77 S.W. 20th Ave., Gainesville, FL 32607, (904) 332-3303.

Seizures

Our six-month-old daughter, Meg, has 20 to 70 seizures daily—even on four seizure medications. Doctors have been unable to diagnose her problem but believe she has a metabolic disorder. She has undergone extensive testing including CT scans, MRI, chromosome studies and metabolic studies. All but her EEG have produced normal results.

Meg is also severely hypotonic and developmentally delayed. She appears normal, but small. She never sucked or swallowed with any coordination and is now fed through a G-tube. She has a wide variety of seizures—most involve apnea. We have been told that Meg has seen the best doctors available and that they have done all they can for her. They refer to her condition as progressive and terminal. We would love to hear from parents of children with similar symptoms.

D.T. & A.T., Texas

Obsessive Compulsive Disorder

I am the parent of a 10-year-old son who has been diagnosed with obsessive compulsive disorder. He is presently on medication for this condition. He also has some learning disabilities.

I would like to hear from parents of children with the same diagnosis to compare notes.

P.P., Massachusetts

Drooling

We have an 11-year-old daughter who has cerebral palsy and is non-verbal. She has a problem with constant drooling. She is a very outgoing child and we

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5006
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

"Bedwetting is something I'll outgrow, but until then, I'll wear GOODNITES.™"

Introducing new PULL-UPS® GOODNITES™ Absorbent Underpants for older children—45 pounds and up. Your child slips them on at bedtime and—accident or not—wakes up to dry sheets, dry pajamas. And a whole new positive attitude.

Even with the super-absorbent lining, GOODNITES™ Absorbent Underpants are so trim, they disappear under pajamas. Nobody needs to know your child is wearing them. And with no sheets to wash, mornings are hassle free. Everyone starts the day right.

We developed GOODNITES™ with the help of pediatricians and other childhood experts. We've put all we learned about bedwetting in a book. For your free copy, send $1.00 postage and handling to GOODNITES™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

473

Circle # 147

We focus on going home

...because that's where the heart is.

Home is where the heart is, but sometimes children with multiple disabilities need special help beyond their parents and school districts. Financing multi-year private school placements can be costly too. But now a school known for its successful individualized education programs is offering an extended assessment and treatment program. That school is Heartspring.

Curt came to Heartspring not because he needed a long-term, intensive program, but because his skills had plateaued, and problematic behaviors were unmanageable. He needed a program with a fresh perspective. With Heartspring's team approach, Curt has the resources he needs: specialists in the areas of special education, audiology, physical, occupational, and speech/language therapies, pediatric development medicine, psychology, and behavior management. Together, they will address his complex needs in a comprehensive, interdisciplinary program designed to continue after he returns to his home environment.

Just think! Curt enrolled this spring, and he'll be going home before school starts this fall. When he does, a Heartspring staff member will return home with him and stay a few days to make reintegration as smooth and effective as possible.

Home is where the heart is, and Heartspring is where the hope is. Let us build a program for your child. Call today.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800- 835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

fear this problem will hinder her social life, especially as she gets older.

We use scarves around her neck to keep her clothing dry during the day. We need to change the scarf approximately seven or eight times daily. Interestingly, she doesn't drool during the night.

Our daughter has had oral-motor therapy since she was a toddler, but we have seen little improvement. We've also tried a medication which did not help. We would like to hear from anyone that has had any success treating this problem. We are particularly interested in hearing of results of surgery to correct this condition.

G.G., Minnesota

Necrotizing Enterocolitis

I am writing in search of others who have a child with necrotizing enterocolitis (NEC). My three-year-old daughter developed NEC at four days of age. I would appreciate any information about this condition. I am looking for information about long-term health and care.

J.M., Colorado

Cogan Syndrome

We are the parents of two children, Derek, who is almost four years old, and Sarah, who is thirteen months old. They have a very rare syndrome called Cogan II or congenital oculomotor apraxia. A child with this condition is unable to voluntarily perform the rapid eye movements called saccades and moves his head because he cannot turn his eyes quickly.

In addition to abnormal head and eye movements, both of my children have low muscle tone which has gradually improved. Derek crawled at 16 months and started walking at 25 months. He is also delayed in his speech.

Sarah is not yet crawling, pulling herself up or walking. She babbles and puts weight on her feet. Her head and eye movements are not as noticeably abnormal as her brother's. Both children are getting physical therapy and Derek is also getting speech therapy.

We would like to hear from other families who have a child or children with Cogan II syndrome. We would like to know about the problems we may face when the children get older.

D.T. & K.T., Kentucky

Clinician's View

Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices.The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays,

by Susanne R. Hays, M.S.,R.N.,C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. **ED 077OD**

Effective Intervention For Self-Feeding Success,

by Christine A. Nelson, Ph.D.,OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. **ED 078OD**

Massage For The Infant With Developmental Disabilities,

by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant's individual concerns. A valued resource for every parent to assist their child's development.

ED 079DD

Near Normal Feeding For Infants With Oral-Facial Anomalies,

by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant's born with cleft lip and/or palate can be very difficult.Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies that parents can follow. **ED 080OD**

Mail to: **Exceptional Parent,** Dept. EP9407, P.O. Box 8 045, Brick, N.J. 08723
Or call **1-(800) 535-1910**

QTY	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES U.S. - $3.50 for 1 item; 75¢ for each additional item. Foreign - $6.50 for 1 item, 75¢ for each additional item.

Sub-Total	
N.J. Res 6% tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

I have enclosed my check payable to Exceptional Parent or charge to my: Visa Mastercard

Account Number: _____ Exp. Date: _____

Signature _____

475

Circle # 227

RESPOND

Chondrodysplasia Punctata

B.H. & V.H. (May 1994) are parents of a three-year-old daughter who has been diagnosed with chondrodysplasia punctata, also known as Conradi-Hunermann syndrome. After doctors told them that there were no other cases of chondrodysplasia punctata in the United States, B.H. & V.H. found another child with the syndrome mentioned in a SEARCH letter published several years ago. They hoped to contact other families who have dealt with this condition.

I felt happy when I read your letter and wanted to let you know that there is someone like your child. That's me! I'm a girl. I am eight years old. I'm in second grade.

I want to tell you not to be scared. I had surgery on my eyes and my back. I'm short, but it doesn't bother me and I'm sure it won't bother your kid. I'm very smart. I can walk, but I need a lift in my shoe.

M.M., Louisiana

Chromosome Translocation

K.H. (March 1994) wanted information on her son's chromosomal abnormality, a complex translocation between chromosomes five and six.

Your letter caught my eye because my three-year-old son has an unbalanced translocation involving chromosomes four and twelve. This disorder has affected his muscle tone and connective tissues. He cannot crawl or walk; he also has a speech delay.

You may want to look into an organization called Chromosome Deletion Outreach (Box 280, Driggs, ID 83422, 208/354-8550). They maintain a directory of families who have children with various chromosomal disorders and try to match people dealing with similar conditions. Five dollars will get you on the mailing list for the newsletter; you can let them know if you would like to be part of the database for matching families.

B.G., Florida

Ischemic Strokes

B.S. and T.S. (April 1994) asked for information about conditions that would cause multiple ischemic strokes in children. Their daughter has been tentatively diagnosed with Moyamoya disease.

Our 17-year-old daughter, Beth, has Moyamoya disease. At age two, she had an ischemic stroke affecting her entire left side. A year later, she had another that affected her entire right side and her speech. At that point, she was diagnosed with Moyamoya disease. Her doctors predicted that she would not live long. About a year later, however, she had surgery to induce circulation to her brain. She didn't have another major stroke but, for years, continued to have daily "mini-strokes," transient ischemic attacks (TIAs).

In December 1992, Beth started taking 20 mg. of Cardene every day. Cardene is a calcium channel blocker that prevents the contraction of arteries and is most commonly used in heart patients. Beth has not had a TIA or migraine since she took the first pill. Now, she is alert and feeling well all the time. She has severe physical disabilities as a result of her strokes, but is a very happy teenager who loves music, malls and the telephone (she uses a TouchTalker with a speaker-phone). We feel like we have had a miracle!

T.E., Illinois

Bleeding During Seizures

J.W. (April 1994) hoped someone could give her a possible explanation for why her daughter, Brianna, bleeds from her mouth and nose when she has seizures.

I was interested to hear that your daughter has bleeding from her mouth and nose when she seizures. Our son, Craig, is twelve and has 4p- (Wolf-Hirschhorn) syndrome. He has had seizures since he was eight months old.

Several years ago, Craig began vomiting bloody material with his seizures. It was always a small amount and stopped quickly. I associated the bleeding with the medication I was giving him for the seizures. However, the medication was given by rectum with mineral oil, like a small enema, so I couldn't imagine how it was affecting his stomach.

Last February, Craig began vomiting blood with a seizure but, this time, the bleeding did not stop. He was hospitalized for a week. Doctors did an upper-gastrointestinal examination and ultrasound. These tests showed nothing except gastric reflux. After coming home, he was fine for two weeks, then began vomiting blood again—and this time, the bleeding was not seizure-induced. The gastroenterologist did a stomach gastroscopy and biopsy. He found that Craig had severe erosive esophagitis, as well as nodemal erosion, which proved positive for a bacterial infection. Craig was put on antibiotics for the infection, and began taking other medications for the gastric reflux which had caused the esophagitis in the first place.

I wanted to alert you to the possibility that your daughter has a similar condition. Craig's esophagus had been slowly eroding for years; we just didn't realize it. Apparently, the stress of the seizures caused periodic bleeding.

B.R., Vermont

Prader-Willi Syndrome

C.M. (May 1994) is the parent of a three-year-old daughter who has been diagnosed with Prader-Willi syndrome. She was looking for information about the lives of children with the same diagnosis.

There are other sources of information in addition to the Prader-Willi Syndrome Association mentioned in the Editor's Note following your *Search* letter. The quarterly journal *Prader-Willi Perspectives* (40 Holly Lane, Roslyn Heights, NY 11577, 800/358-0682) sponsors the Prader-Willi Syndrome International Information Forum, a worldwide network of parent-to-parent and parent-to-professional referrals that brings together people with similar concerns.

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,

Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

*US funds only. Canada $30 per year. Other foreign countries $33 per year.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34G1

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

*US funds only. Canada $30 per year. Other foreign countries $33 per year.

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34G1

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,

Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

See reverse side for subscription details

Membership is free, and members receive a newsletter, as well as 24-hour-a-day access via telephone, fax and e-mail.

The Prader-Willi Foundation (223 Main Street, Port Washington, NY 11050, 800/253-7993) is another valuable source of information. The Foundation also issues newsletters and other printed material of interest to families.

S.T., New York

Ritalin and Autism

L.S. (May 1994) is the parent of a four-year-old boy with autism. A doctor had recommended the use of Ritalin to improve her son's concentration and decrease his distractibility. L.S. wondered whether the medication would be effective. She also wondered about possible side effects.

Our nine-year-old son, Jeffrey, has been diagnosed with autism and attention deficit hyperactivity disorder (ADHD). He has been on Ritalin for a year. Jeffrey started with a dose of 2.5 mg. a day. He now takes a 5-mg. dose three times a day.

The medication has been effective in improving Jeff's attention and focus, especially at school. Most days are good; some are great; a few are days when it seems as if he didn't take the medication. The only "negative" side effects have been decreased appetite and a sometimes too-intense focus on what *he* is doing. Of course, factors other than the medication affect Jeffrey's focus and learning. These factors include the type and length of the activity in which he is involved, transitioning issues, the amount of encouragement he is receiving and his general health and mood. Of course, these are factors that affect all of us!

G.S. & B.S., New York

☐ I have a four-year-old son with autism. For the past year and a half, he has been taking 2.5 mg. of Ritalin a day. We asked our physician to try Ritalin with our son because we have two daughters and numerous other relatives with ADHD. We had seen autistic-like behaviors in them and thought, "If Ritalin helps them, maybe it could help our son."

Before this, my son would not respond to noises, his name, people—anything. He had all-consuming, self-stimulating behaviors that included running in circles while twirling his fingers in front of his eyes.

The doctor started him on a low dose (2.5 mg.) of Ritalin because of his size and age. He became able to sit and pay attention at school, at home and during therapy sessions. He started to respond when his name was called and began to follow simple commands. Self-stimulating behavior also decreased substantially—to the point where he would stop "self-stim" when told to do so.

When the doctor increased the dose to 5 mg. every morning, our son began having frequent tantrums involving screaming, crying and physical aggression. After a month—we thought this was a fair trial—we brought him back down to 2.5 mg. The tantrums subsided. Then, we tried 2.5 mg. twice a day; he responded by being very whiny and resistant to any activities that were not of his choosing. So, we went back to 2.5 mg. and a happy, loving child.

K.G., Arizona

☐ Our seven-year-old son is mildly autistic. When he was almost four years old, he was diagnosed with pervasive developmental disorder (PDD) and ADHD. The doctor prescribed 2.5 mg. of Ritalin twice daily. After a few weeks, we began to see frightening side effects. He began biting and scratching himself until he bled. He banged his head repeatedly. Sometimes, he would go into what we called a "robotic state." We could not get his attention, make eye contact or obtain any response, even when we turned his favorite videotape off—he just stared into space. Then, all of a sudden, he would give out a blood-curdling scream, cry hysterically and slap his face with both hands. He also slept much more than normal, which lowered his physical activity level. We disposed of the medication and within a few days, had our son back again.

We no longer have him on any type of medication. He is doing very well at school; we have learned to deal with problems as they come up.

L.C., Illinois

NEW!
Kids need their independence too!
the Littlest Rascal
Especially designed and engineered, the Littlest Rascal, provides kids with safe, fun, dependable independent mobility. Features include easy-to-use "one hand" controls, automatic brakes, padded seat and adjustable speed control.
Call, toll-free.
1 800 662-4548
Or write.
Electric Mobility
1 Mobility Plaza, Dept 5757
Sewell, NJ 08080
ELECTRIC MOBILITY
Circle # 152

LETTERS

Kimberly-Clark "Listens and Cares"

A letter in the September 1993 issue of *Exceptional Parent* magazine encouraged interested readers to write to Kimberly-Clark Corporation, the maker of PULL-UPS® training pants, to ask for a larger, PULL-UPS-style product for older children.

The response from your readers was overwhelming. At the time, we were able to tell them that the product they were asking for was under development. Well, I'm happy to say that the product is now available in stores throughout North America.

We recently introduced PULL-UPS® GOODNITES™ absorbent underpants for older children who need absorbent protection. This new product has a white, cloth-like outer cover and offers children who need it a discreet, trim-fitting undergarment that provides maximum absorbent protection.

The best news is that parents who have tried this product for their children love it. We have already received many letters thanking us for listening and for providing a product that uniquely meets their children's needs for discreet protection.

Please pass on my thanks to your readers who were concerned enough to contact us about this product. Believe me—we listen and we care. We also welcome any comments your readers may have about our new GOODNITES™ product.

Thomas J. Falk
Group President, Infant and Child Care
Kimberly-Clark Corporation

Learning Disabilities and Inclusion

I am the parent of two children with learning disabilities and a long-time subscriber to *Exceptional Parent*. The timing of various articles continues to amaze me! Many times, when searching for specific information, along came my copy of *Exceptional Parent* with exactly the information I needed. The April 1994 issue and Dr. Edwin Martin's guest editorial, *Inclusion: Rhetoric and Reality*, was one such case.

The information Dr. Martin provided is something I have been seeking. Unfortunately, many educators do not understand learning disabilities and, as a result, our children suffer. Parents Aware for Children, an advocacy group with which I am involved, has made a proposal to the local public schools to provide inservice training on learning disabilities and attention deficit disorder for regular and special education teachers during the 1994–95 school year. Dr. Martin's article gives a good overview of the complexities of inclusion for children with learning disabilities. I know we can use this information to help children with learning disabilities succeed. Thank you for a wonderful magazine and a superb article.

J.W., New Mexico

Thank You

A recent mailing I received from the National Tuberous Sclerosis Association (NTSA) inspired me to write to you. I was surprised to learn that NTSA began as the result of a mother's *Search* letter published in *Exceptional Parent* 20 years ago.

My husband and I are actively involved with NTSA because our four-year-old daughter has tuberous sclerosis. We are lucky because she is doing

EXCEPTIONAL PARENT

▸ *To reach out to parents of children with disabilities and special health care needs.*

▸ *To empower mothers and fathers by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
MARILYN ROSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

450

GM MOBILITY℠ PROGRAM

Maintain your daily independence through the General Motors Mobility Program for Persons with Disabilities.

It starts with a toll-free call to our GM Mobility Assistance Center. We'll identify your local driver assessment centers, list your area's installers of adaptive driving devices or vehicle modifications and suggest which GM cars and light-duty trucks might work best for you.

Next, whether you buy or lease a new GM vehicle or dealer demo model, we'll reimburse you for the cost of adapting it–or for the reinstallation of your own adaptive equipment–up to $1000. Qualified customers can finance the cost of the vehicle and any modifications through GMAC in a single transaction at participating dealers.

(Reimbursement for leased vehicle adaptation available only upon lessor's approval to adapt vehicle.)

We're making every day Independence Day.

The people at GM, and GM dealers nationwide, know how important mobility is to your everyday life. Call us today. Or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer and find out how the General Motors Mobility Program can help make every day Independence Day for you.

Call toll-free: 1-800-323-9935
(TDD users: 1-800-TDD-9935)

- **Reimbursement of adaptation costs, up to $1000**
- **Financing available through GMAC**
- **Information on driver assessment centers and adaptive equipment installers**
- **Free resource video, "On The Move Again"**
- **24-hour Roadside Assistance**

General Motors.

Our Toilet Supports are so adjustable toddlers thru adults can use the same one. We have High Back and Low Back versions. Pommels, urine deflectors, foot rests and smaller seats for young children are available.

Our **NEW** Bath/Shower Chairs are the most adjustable ones made. We have 3 models - an **Elevated**, a **Standard**, and a **Roll-In Shower** chair. Each model has 6 sizes to maximize the time of its use. Your child and you

For a free brochure call or write:

The Adaptive Design Shop

12847 Pt. Pleasant Drive
Fairfax, VA 22033
703-631-1585

Circle # 3

very well; her seizures are controlled and she has no developmental delays. NTSA, and the other families we have met through this organization, have been a godsend to us.

Last July, our son, Peter, was born. At four months of age, we learned that he had complete absence of the left hemisphere of his cerebellum and had some brainstem damage. He may also have a profound hearing loss in one ear. Our neurologist believes that Peter probably suffered an intrauterine stroke sometime in the second trimester and that there is absolutely no relationship between his disability and our daughter's.

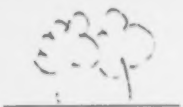
At almost 10 months of age, Peter also is doing remarkably well. His intellectual and fine-motor skills are on target for his age, and his gross-motor skills are progressing. His most obvious impairment is an equilibrium problem; he holds his head with his right ear "down" and looks at the world sideways. Our neurologist and many other doctors say Peter is one of a kind.

As is the case with most parents of children with disabilities, we do not know what Peter will do in the future. But I have come to realize that nobody really knows what will become of their children—whether they have disabilities or not—so I no longer worry constantly about my children's future; I just work hard with them in the present.

Thank you again for being available to parents like us!

S.D.T., Maryland

EDITOR'S NOTE: NTSA can be contacted at 8000 Corporate Dr., Ste. 120, Landover, MD 20785, (800) 225-6872.



Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Associations with leading specialists and major medical centers

Affiliation with SUNY

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

Circle # 8

An Excellent Resource

As a parent of a two-year-old son who has cerebral palsy, severe developmental delay, a seizure disorder and blindness, I find *Exceptional Parent* to be an excellent resource. Nothing is more comforting than stories of other families in similar situations. It is very discouraging to be unable to look to the future, because no one—including doctors—can predict what my son will be capable of doing.

Although a few of the articles have been difficult to read, I have forced myself to continue. I know that stories about the deaths of these beautiful children may one day hit home. These articles have made me more aware of how precious life is. I appreciate every second I have with my son. I hope more articles about coping and preparing for a child's death will appear in future issues. To the brave parents who have written these stories—I thank you and pray for you everyday. I also pray for every parent who has a child with a disability. God bless us all.

L.M.Z., New Jersey

In Defense of My Daughter

I had to write in response to Judy Horton's article, *In Defense of My Daughter* (March 1994), which detailed the author's method for dealing with children teasing her daughter.

My 10-year-old daughter, Josie, is hyperactive. She jumps, screams and sometimes, curses. She has a hearing aid. She also gets really close to everything because she has a visual impairment.

Over the years, through trial and error, I have developed a system that seems to work when other kids tease or, more often, just stare. If the stare is real intense and I have time, I ask, "Do you have a question about Josie?" Sometimes children beat me to it and ask, "Can she see?" or "How come she does that?"

Children's curiosity—their usual first reaction to Josie—creates a "teachable moment." I describe some of Josie's disabilities using simple language. One child reacted to my explanation by saying, "Poor thing."

I said, "Don't feel sorry for her. Just be a friend."

Sometimes, kids have made rude comments about Josie or to her. Again, I first ask if they have a question about her. I try to assume that kids will behave responsibly if they have good information. So far, I haven't had to go beyond giving information in a very matter-of-fact way, always acting like disability is just one part of the normal human condition.

Incidents with my son, who is black, have also provided me with lessons in dealing with prejudice. The first time kids teased him, I lost my temper and threatened to tell their parents. However, I didn't think that solved the underlying problem. So, next time it happened, I walked up to the kid and used an idea I got from a book. I said, "Name-calling hurts feelings." To my complete amazement, the kid turned away, totally embarrassed, and left my son alone after that.

If education fails to work, however, I would endorse Horton's firmer methods! I think it is necessary to come to terms with your child's disability before one is able to help your child's peers do the same.

M.H., Hawaii

Circle # 46

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Introducing the Troubleshooter

Parents of children with disabilities face an enormous number of challenges. They must cope with the physical and psychological difficulties inherent in a child's disability or condition. In addition, they must deal with school systems, government agencies, architectural barriers and a society that sometimes exhibits subtle negative attitudes or open hostility toward people with disabilities.

The inability to obtain health insurance coverage for children with disabilities can compound the frustrations of their parents. It can also lead to severe economic hardship. Even for parents who are fortunate enough to have health insurance, the struggle to obtain appropriate benefits can be overwhelming.

Parents of children with disabilities often need help dealing with health insurance. *Health Insurance Troubleshooter* is dedicated to providing that help by offering practical suggestions in response to questions from readers. In addition, the department will focus on general issues and changes that may occur as a result of the health care reforms being discussed on the federal level by President Clinton and congress, and by the governments of various states.

Future installments of *Health Insurance Troubleshooter* will discuss ways that parents can obtain health insurance for their children with disabilities, even if they have had difficulty in the past.

We will also review claim problems resulting from difficulties in communication between insurance companies and consumers. A common problem, for example, involves the situation in which an insurance company rejects a claim—for a hospital stay, the purchase of a wheelchair, x-rays, diagnostic tests or other services—by using the phrase "not medically necessary." This can be economically and emotionally distressing.

In many cases, however, "not medically necessary" simply means that the insurance company is lacking adequate paperwork to document the medical necessity of the product or service in question. In such cases, all that is required is a letter from a doctor explaining that the expense was necessary for a specific illness or condition. Insurance companies generally consider that kind of paperwork, or "documentation," to be essential, and won't pay for a claim until it's on file.

Ideally, of course, insurance companies should communicate more clearly and more effectively with consumers. In fact, they insurance companies generally try to do so. However, due to the number of legal challenges insurance companies have faced over the years, companies have become very careful in the way they phrase explanations to consumers. Unfortunately, misunderstandings are common.

One reason for the occurrence of misunderstandings between insurance companies and consumers has to do with the use of technical terms and phrases. Such terminology may be well understood in the health insurance industry but is frequently misunderstood by the general public. Furthermore, as companies have grown larger, they have come to depend on pre-written, computer-generated, rather than personal letters.

Consumers can understand insurance company behavior better by knowing how insurance companies work and what they mean by specific technical terms and phrases. This also can increase the likelihood that claims will be properly paid.

I first became involved with health insurance problems 15 years ago, when my disability—spinal arthritis—resulted in a need to use an electric wheelchair. In order to ensure that my claims were properly processed, I had to learn how my insurance company worked. A few years later, when the public school district in which I teach switched insurance companies, I was hired to help solve the insurance problems that many staff members were experiencing. Three years ago, I began to write a "Question and Answer" column on health insurance for a large newspaper.

As a result of these experiences, I have been involved in helping to solve hundreds of health insurance problems. I have had the opportunity

continued on page 67

PRODUCT NEWS

Lightweight Portability Solves Transport Problem

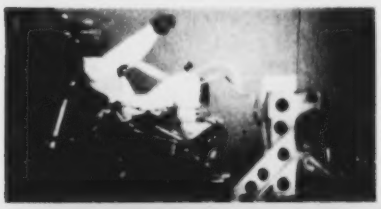
Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

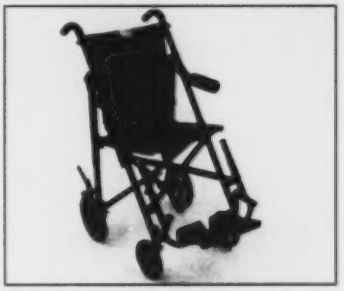
Full Range of Accessories

A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

New Bus/Van Tie-Down Models

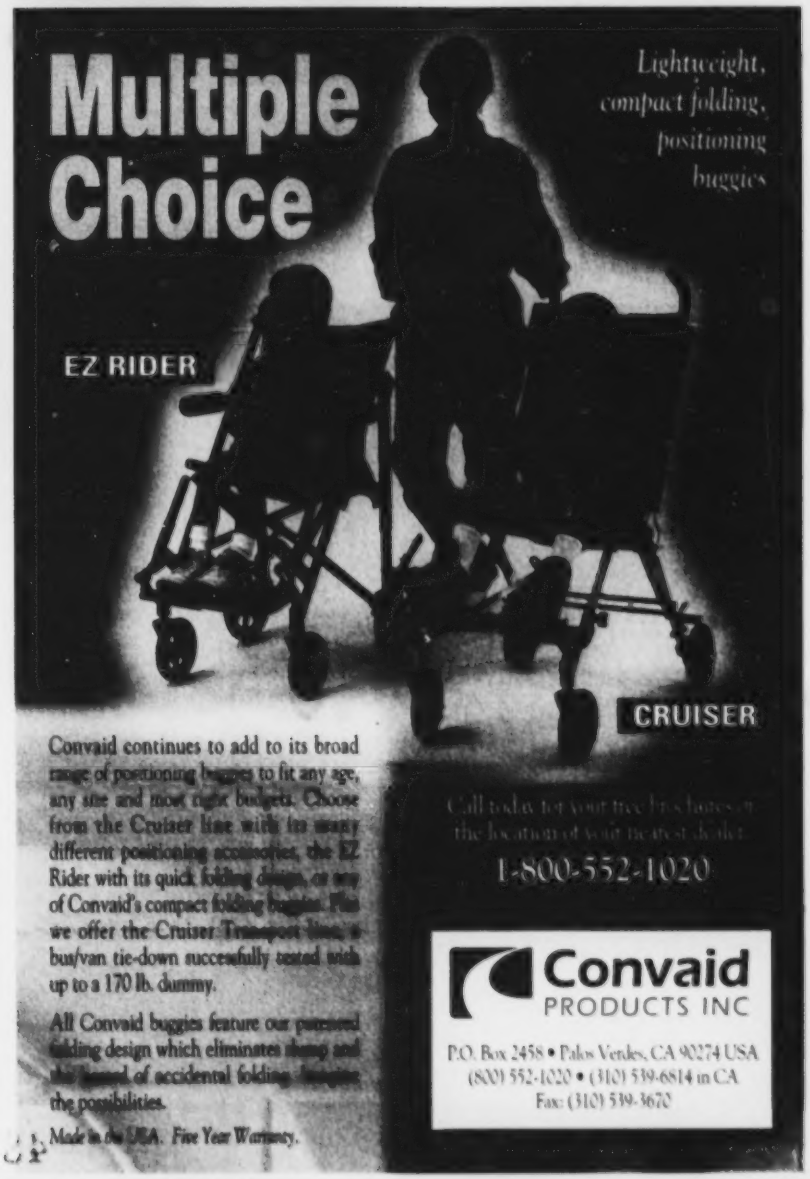
Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.



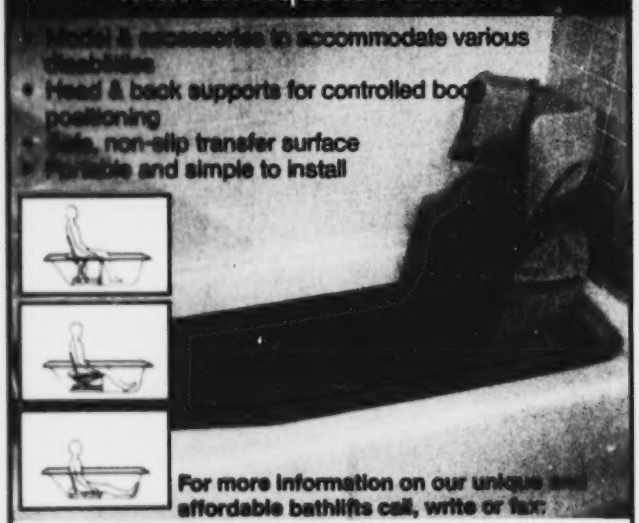


Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.


Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.
All Convaid buggies feature our patented folding design which eliminates clamps and the hazard of accidental folding. Compare the possibilities.
Made in the USA. Five Year Warranty.
Call today for your free brochure or the location of your nearest dealer
1-800-552-1020
Convaid
PRODUCTS INC
P.O. Box 2458 • Palos Verdes, CA 90274 USA
(800) 552-1020 • (310) 539-6814 in CA
Fax: (310) 539-3670

MAKE BATHTIME WITH YOUR CHILD A PLEASURE NOT A CHORE . . .
With an Aquatec Bathlift



- Model & accessories to accommodate various disabilities
- Head & back supports for controlled body positioning
- Safe, non-slip transfer surface
- Portable and simple to install

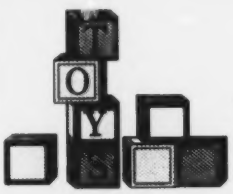
For more information on our unique and affordable bathlifts call, write or fax:

AQUATEC® The Bathlift Specialists
Health Care Products, L.P.
PIIP-ICM Building • 1003 International Drive
Oakdale, PA 15071-9223
Phone: 412-695-2122 • Fax: 412-695-2922

Circle # 128

SWITCH ON THE FUN WITH INVOTEK TOYS

InvoTek toys are the perfect gift for any severely physically involved child. Popular toys for girl and boys of all ages have been modified to be switch accessible. Toys that are presently available include: **Tiger® 2-XL™ Talking Robot, My Little Smart first words™**, and **Tyco® Electric Racing Set**. Order soon to ensure holiday delivery. Limited quantities are available. Call InvoTek for a catalog and pricing.



INVOTEK CORPORATION
700 West 20th Street, ENRC
Fayetteville, AR 72701
1-800-576-6661

Circle # 211

Money skills? cooking? shopping? grooming? housekeeping? Communication aids? software? videos? We've got 'em.
And this year we're offering "family value pricing", discounts for individuals and family members.
Think about us for holiday gift giving.
Call or write to reserve your copy of *Options* today!

Attainment company

P.O. Box 930160 • Verona, WI 53593-0160
1-800-327-4269 • FAX 1-800-942-3865

Circle # 219

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

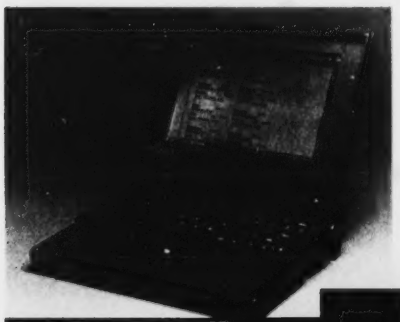
☐ I'm interested in community involvement. Please send more information about Civitan service clubs in my community.
☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name_____
Address_____
City/State/Zip_____
Telephone Number ( ) _____

CIVITAN INTERNATIONAL, P.O. BOX 130220, BIRMINGHAM, AL 35213. (800) CIVITAN

Circle # 186

On Aisle 17, we're selling Macintosh computers by the bundle.



Apple PowerBook 145B

A bundle is a total solution consisting of a Macintosh®, an Apple® printer and a wide variety of specially selected software.

Aisle 17 is filled with Macintosh solutions. For children and adults with disabilities. And for rehabilitation professionals. Now the power of personalized computing is as easy to buy as it is to use.

Apple StyleWriter II

Call Aisle 17 today. You'll find friendly people, fully prepared to help you meet your personal computing needs.

1-800-600-7808, 1-800-755-0601(TTY). The Apple Computer Disability Solutions Store.

The Dangerous Yew

And other tales of growing up with blindness

by Sally Caroline

There is, of course, nothing inherently amusing about blindness, or any other disability for that matter. Blindness imposes all sorts of frustrating limitations and complicates some of life's most basic tasks. Still, life goes on—busy, demanding, annoying… and *yes*, funny. Our family members, like those of families around the world, are bound together by collective memories that have been built up over many years. My daughters, Rebecca and Melinda, are young women now, off living their own lives, but many of the funny stories that the family still retells revolve around Rebecca's blindness.

Your Other Left

As if blindness was not disorienting enough, Rebecca also has had to cope with a slightly defective mother. Now, I don't know exactly how one would define *my* disability—directional dyslexia, perhaps? It isn't that I don't *know* my right from my left; it's just that I can't seem to name them correctly with any consistency. One day, when Rebecca was in third or fourth grade and no longer had "traveling vision," she came into the living room to ask if I knew where the three-hole punch was. Either her sister or dad had used it and failed to return it to its proper place on the kitchen shelf. I glanced around, spotted it abandoned on the floor and replied, "It's right here, on the floor about five steps to your left."

Rebecca confidently headed off, as I suddenly realized it was to *my* left all right, but since she was facing me, it was to *her* right.

"No, no!" I exclaimed. "I meant your… uh…"—the word had deserted me—"uh… your *other* left."

Becca stopped in her tracks and shot me the most incredulous of looks. Then she slowly and patiently asked, "Would that be the 'left' that the rest of us call 'right,' Mom?"

That incident proved to be a learning experience for Rebecca. Even today, if I give her directions, she takes an exploratory step or two in the direction I name and waits for me to correct myself. Wise move.

Playing "Popeye"

Rebecca had always attended public school in our small town. Over the years, as her vision deteriorated, her friends adjusted quite matter-of-factly. When she was in fifth grade, Rebecca had to have both eyes removed. They were replaced with ocular prostheses, often called "glass eyes," though they are now made of some wonderful type of plastic. Becca, along with her classmates, took this new development in stride.

Shortly after Rebecca's return to school, while her body and her prostheses were still adjusting to each other, she attended an all-school assembly with her class. During the assembly, Becca suddenly sneezed, and out popped one of her prostheses!

The young man sitting next to her saw where it had landed, retrieved it for her, and handed it to her, saying simply, "Here's your eye, Becky."

"Thanks a lot," she replied, and as unobtrusively as possible, popped it into her mouth to clean off any dust and dirt, then, replaced it in its socket. After the assembly, she went to the school nurse because she wasn't quite sure if there was something else she should do to clean the prosthesis and avoid infection. Apparently, she explained the situation to the nurse—by this time a very good friend—by saying, "I just got through playing Popeye."

The very idea quite discombobulated the poor woman—this was not an everyday event in the life of a small-town school nurse—and she called me in a bit of a dither. Well, we all were pretty new to this prosthesis business, but I knew enough to be able to reassure her: "As long as Becca reports no discomfort that would

ILLUSTRATIONS BY MICHAEL MORAN

indicate dirt in the socket, just rinse the eye, right in place, with some sterile saline. We'll do a thorough cleaning of the socket and prosthesis when she gets home." That nurse eventually went into a different kind of nursing and has now retired, but I still run into her around town and she always recalls "the day Rebecca played Popeye!"

Kids Say the Darndest Things

Kids are amazingly forthright and direct, and also wonderfully accepting once their questions have been answered. Fortunately, Rebecca has never been bothered by honest questions about her condition and has always been willing to answer them as clearly as possible. A family friend has a daughter about five years younger than Rebecca. When this little girl was about six, she evidently began to think about Rebecca's blindness in practical terms. The kids were having a snack one day when Helen turned to Rebecca and asked, "How do you find your mouth?"

This was one question Rebecca really couldn't answer—you don't need to see to find your mouth, you just do it! Finally, Rebecca said, "Well, close your eyes and take a bite of your cookie."

Helen did.

"How did you find your mouth?" Rebecca asked.

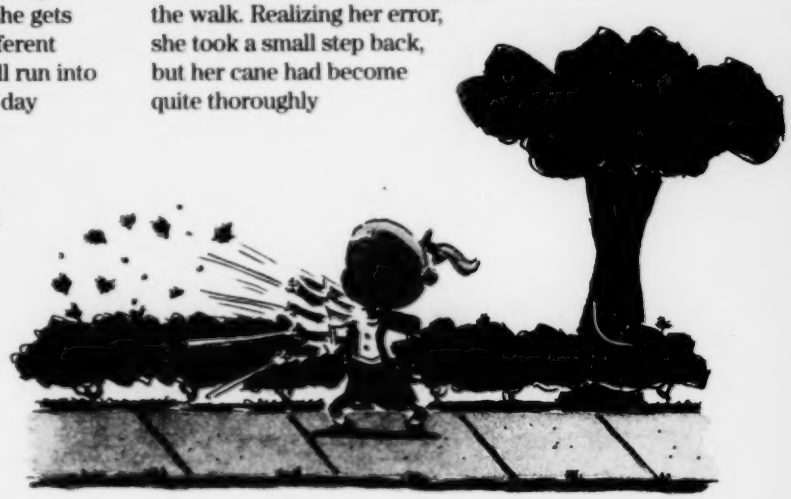
A big smile spread over Helen's face and she looked relieved. Apparently, it had bothered her quite a bit that Becca might not be able to eat without lots of trouble. "I guess it's not a problem, huh?" she said.

"Well," Becca answered, "Sometimes it's hard finding food on your plate, or making it stay on your silverware. But no, finding your mouth is not a problem." Kids think about the most interesting things and ask the best questions.

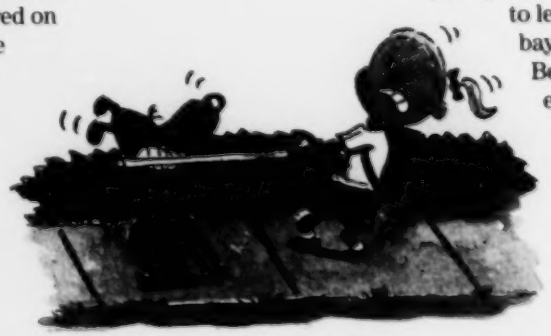
Battling Bushes and Dogs

Like most suburban mothers, I ran a "taxi service" throughout all the years my daughters were in school. One day I had to pick Becca up early to go to an appointment. We had worked out a system whereby I parked at the end of the drive nearest a side door. Becca would step out that door and I'd toot the horn once, so she knew I was there.

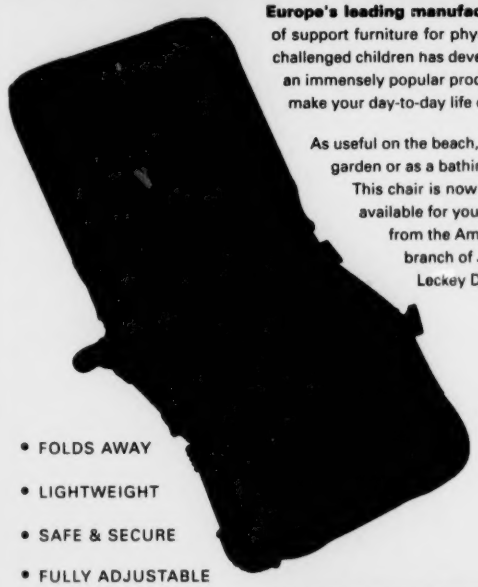
That day, she appeared on time, backpack over one shoulder, white cane in the other hand. She had to come down a short paved path and make a 90 degree turn onto the drive, a route she traveled regularly. But for some reason, this day, she made her turn a few steps early. Her cane promptly encountered a low yew bush planted beside the walk. Realizing her error, she took a small step back, but her cane had become quite thoroughly entangled in the yew's branches. She proceeding to engage in what resembled a sword fight for perhaps 30 seconds before managing to extricate her cane. This looked so funny that by this time she opened the car door, she found her mother quite collapsed with a fit of the giggles. After I'd recovered enough to explain myself, we both collapsed into another fit of the giggles and arrived at our destination still periodically chuckling. This has evermore been known in our family as the tale of *Rebecca and the Dangerous Yew*, which she bravely battled into submission with her sword-cane.



About the same time as the yew incident, Rebecca encountered another adventure involving her cane. In middle school, classes were held in two separate buildings set close together on the same lot. Rebecca would leave one class a few minutes early in order to cross to the other building ahead of the mob scene that erupted at the end-of-period bell. As she was crossing the courtyard one day, up bounded a large, playful dog who grabbed Rebecca's "stick" in his powerful jaws and tried to make off with it. A tug-of-war began. Neither side could win, but neither would back off, either. Fortunately, a couple of Rebecca's classmates chanced to look out the window and see her predicament. With the teacher's permission, three young men came running out. Two got the dog to let go of his "stick" and held him at bay, yelling, "Make a break for it, Becky!" The third boy quickly escorted Becca the rest of the way across the courtyard and into the other building. Of course, they all found this riotously funny, and that cane, now long since retired, still bears quite a number of canine tooth marks.



Adjustable Bath Chair



Europe's leading manufacturer of support furniture for physically challenged children has developed an immensely popular product to make your day-to-day life easier.

As useful on the beach, in the garden or as a bathing aid. This chair is now easily available for you direct from the American branch of James Leckey Design.

- FOLDS AWAY
- LIGHTWEIGHT
- SAFE & SECURE
- FULLY ADJUSTABLE

LECKEY
SUPPORT FURNITURE
1250 Main Street, Waltham, M.A. 02154-1763
Tel: (617) 891 9414 Fax: (617) 891 9562
Freephone: 1–800–LECKEY–0

Circle # 212

Laughter, the Best Medicine

Living with illness and disability is certainly no day at the beach; over the years, our family has shed many tears. But Rebecca came into this world with a sunny disposition and a sense of humor that has never completely deserted her, even during the worst of times. Her ability to laugh has saved us all. Sure, sometimes it was a kind of "black humor," but we've managed to laugh our way through some pretty horrible things. Nowadays, I read about current research that shows that laughter actually can be a useful therapy. I believe it... but, I'm glad we learned to laugh even before it became "medically correct."

Family Portrait: *(from left) Sally, Rebecca, Melinda and Peter Caroline.*

Sally Caroline and her husband, Peter, have lived in Hamilton, Massachusetts for 24 of the 27 years they have been married. Their daughters, Rebecca and Melinda, are now adults and on their own. For many years, Sally worked as a special education tutor. When the grant money that funded that position ran out, she began a new career in retail sales which she describes as "not as challenging, but a lot of fun."

SPORTIME
Abilitations™

...The World's Largest Selection Of Therapy Balls To Meet EVERY Child's Needs!!

Sportime can offer you Therapy Balls in a range of colors and sizes from 45cm to 120cm. You can choose from traditional colored **Physio-Gymnics®** or clear **Opti-Balls®** with write-on/wash-off surfaces. We also have **Bellballs®** and **Visualisers®** which provide auditory and visual feedback.

OUR PATENTED PHYSIO-ROLL™
Sportime's unique **Physio-Roll®** provides security and comfort for your children. The benefits of ball therapy are innumerable; yet for some children, the movement of the ball can be frightening. Unlike traditional balls,the Physio-Roll limits movement, proving a secure atmosphere for encouraging mobility, balance, proper sitting, vestibular motion and strengthening. A Physio-Roll may be used to benefit nearly all persons of any age. For more information on these and other therapeutic products from **Sportime® Abilitations™**, call for your **FREE** catalog at: **1-800-283-5700.**

AAD20 **One Sportime Way • Atlanta, GA 30340**

Order Toll Free 1-800-283-5700

Circle # 189

490

CHARLES C THOMAS • PUBLISHER

☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 308 pp., 13 il., 1 table,59.75.

The purpose of this handbook is to help children who learn differently and who have been failing or underachieving in school. It does this by giving enough information for an adult with no previous teaching experience to design and implement an effective remedial program. Most parents feel guilty when their children do not do well in school, and the first section is designed to help parents make realistic changes in the physical and emotional environment at home and at school. The second section gives simple objective tests that show what a child knows and what he needs to learn. It evaluates the maturity of skills in memory, visual-perception and auditory-perception, as well as skills in reading, spelling, phonics, and math. The final section shows how to use test findings to determine which subjects should be taught and specific techniques for teaching them.

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.

☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.

☐ Trief, Ellen—**WORKING WITH VISUALLY IMPAIRED YOUNG STUDENTS: A Curriculum Guide for Birth–3 Year Olds.** '92, 230 pp. (7 × 10), 3 il., $41.75.

☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.

☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $50.50.

☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, $52.75.

☐ Fine, Aubrey H. & Nya M. Fine—**THERAPEUTIC RECREATION FOR EXCEPTIONAL CHILDREN: Let Me In, I Want to Play.** '88, 362 pp. (7 × 10), 9 il., 22 tables, $59.75.

☐ Tuttle, Dean W.—**SELF-ESTEEM AND ADJUSTING WITH BLINDNESS: The Process of Responding to Life's Demands.** '84, 336 pp., 13 il., $44.00.

☐ Lukken, Miriam W.—**READ THIS BOOK BEFORE YOUR CHILD STARTS SCHOOL.** '94, 250 pp. (7 × 10), 5 il., 1 table.

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 284 pp. (6¼ × 9¼), 100 il., 14 tables, $42.75.

☐ Love, Harold D. & Freddie W. Litton—**TEACHING READING TO DISABLED AND HANDICAPPED LEARNERS.** '94, 280 pp. (7 × 10), 8 il., 23 tables.

☐ Williams, Leslie A. & Lucile S. Arntzen—**A PRACTICAL APPROACH TO RSP: A Handbook for the Resource Specialist Program, 2nd Ed.** '94, 120 pp. (7 × 10), 2 il., 4 tables. $29.75.

☐ Giordano, Gerard—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $36.75.

☐ Vaughan, C. Edwin—**THE STRUGGLE OF BLIND PEOPLE FOR SELF-DETERMINATION: The Dependency-Rehabilitation Conflict; Empowerment in the Blindness Community.** '93, 256 pp. (7 × 10), 3 il., $41.00.

☐ Kass, Corrine E. & Cleborne D. Maddux—**A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice.** '93, 222 pp. (7 × 10), 3 il., $45.75.

☐ Durán, Elva—**VOCATIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION.** '92, 182 pp. (7 x 10), 21 il., $37.75.

☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.

☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¼ × 9¼), 113 il., 19 tables, $59.75.

☐ Higgins, Paul C.—**The Challenge of Educating Together DEAF AND HEARING YOUTH Making Mainstreaming Work.** '90, 198 pp. (7 × 10), $38.25.

☐ Hughes, Barry K.—**PARENTING A CHILD WITH TRAUMATIC BRAIN INJURY.** '90, 111 pp. (7 × 10), 3 il., $28.50.

☐ Harley, Randall K., Mila B. Truan & LaRhea D. Sanford—**COMMUNICATION SKILLS FOR VISUALLY IMPAIRED LEARNERS.** '88, 356 pp. (6¼ × 9¼), 41 il., $53.00.

Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice

2600 South First Street Springfield • Illinois • 62794-9265

Circle # 10 491

A Date to Remember

A young man's "dream date" turns into a nightmare.

by John Gray

I was born in 1948 and diagnosed with cerebral palsy when I was two years old. My balance was poor, but I learned to walk. I can't control my hands well. My speech is slow and slurred, but understandable. Although my physical disabilities are severe, my intelligence is not impaired.

When I was growing up, I was not allowed to attend the local public school. The school system sent a tutor to my home for two hours a day, two days a week. My parents realized that I would never receive a complete education unless I entered a state school. When I was 10 years old, I went to live in an institution. I missed my home and family terribly. Finally, when I was 15 years old, my parents took me out of the institution and fought to get me into the local high school. The teachers at school knew that I was bright, but because of my disabilities, I was not considered "college material." I got my first job, as a light-duty janitor, at age 21.

I started to think about dating. This is the story of one of my first dates—one that turned out to be so embarrassing that I have never had the courage to write about it until now.

Grandma's house at Christmas: *John and his aunt, Evelyn, in 1964.*

It was 1969 when I got my first job, and most people had never seen individuals with disabilities in the work force. Even after some time, many people in my workplace continued to be uncomfortable with me.

The closest relationship I developed there was with a woman who worked in the building. Lynn and I started out by greeting each other as she would arrive for work. Eventually, our interactions escalated into teasing. Sometimes I would fall on a floor I had just waxed and after making sure I was all right, she would make a comment like, "I think that's enough wax on the floor, don't you?"

When Lynn would come into work late on a Monday morning, I would say something like, "Those Monday morning hangovers can be rough, can't they?"

Then the bad news came. She was going to move away in a couple of weeks. I was heartbroken. I thought, "There goes the only one who ever noticed me." Of course, I couldn't let her know how I felt, so I just continued laughing and joking with her as usual.

The Tease that Turned into a Date

Lynn's last day of work was a Friday in the middle of August. As we were preparing to leave, I had to tease her one last time. "Can I come over for a swim this weekend?" I asked.

"Sure," she replied.

Whoa! What did she say? Alarms were going off inside my head. She asked for my address so she could pick me up the next day at noon. I stuttered my address at her while she grinned.

I lay awake that night thinking of ways to cope with possible problems that could arise the next day. Only when I was sure I had covered every eventuality did I allow myself to drift into a restless sleep.

The following day, Lynn arrived at 12:00 sharp. I climbed into the car, and we were off. We chatted and giggled about work-related subjects.

Then it was time to meet her parents. They smiled at me but kept shooting mournful looks at Lynn. I tried to lighten the atmosphere by telling a few jokes, but because her parents were having difficulty understanding my speech, they didn't laugh.

The afternoon started with a cookout. I knew Lynn's parents were trying not to stare at the way I handled my utensils. But I could feel them watching me. I was sure they were going to jump up, grab my silverware and start feeding me. Somehow, we survived the meal.

Fantasy Meets Reality

After lunch, Lynn asked me if I would like to go for a swim. This was a scene I had played out in my mind many times. As for many young men my age, the "pool scene" was a favorite fantasy: A beautiful young woman in a two-piece bathing suit beckons me into the pool. As I suavely slide into the water, the young woman slips into my arms and tells me how big, strong and capable I am… Oh, did I mention that in this fantasy, I look exactly like John Wayne?

Of course, reality has a way of intruding on fantasies. Few of us are built like John Wayne. Add a

Mobile Play Equipment Standard Features

- Adjustable Speed Control
- Multiple Switch Jack
- Two 6 Volt Batteries
- Battery Charger

Custom Accessories [Electronic Kits Available]

- Proportional Remote Control With Emergency On/Off Switch
- Adjustable Seating
- Safety Lap Belt
- Proportional Joystick
- Switches
- Magic Arm
- Head Support Collar

Learning Can Be Fun When You Put A Child In The Driver's Seat

Manual dexterity and eye hand coordination are essential developmental skills for a youngster with a disability. Mobile play equipment custom fitted with electronic control systems from Innovative Products enables a young child to acquire them in a safe, enjoyable way. The thrill of operating a mobile play vehicle provides plenty of motivation for learning the essential skills a child will need as he grows older. These high quality, battery-powered mobile play vehicles are equiped with custom seating and safety harness. Control systems meet the needs of each child and maximum safety is assured by an optional adult operated radio control override.

Innovative Products is leading the way to a better tomorrow for children with disabilities.

BEACH ▶ BUGGY

The Pink & White BEACH BUGGY will please every youngster and provide many hours of enjoyment. This quality built play vehicle is a winner.

▲ BIGFOOT

The Rough and Ready 4 X 4 styling gives this vehicle special appeal. This high quality play equipment is from BIGFOOT 4 X 4 Inc. of St. Louis, MO. Photo used by permission.

Now, with electronic switch activated [illegible] everyone can enj[illegible]

CALL NOW

1-800-950-5185

Innovative Products Inc.
830 48th St. Grand Forks, ND 58201
A Leader In Electronic Control System Technology For Persons with Disabilities

Circle # 42

493

BOWLING

With Pose-I-B[illegible] powered, switch[illegible] everyone can pe[illegible] popular sport. Por[illegible] accessible, it can b[illegible] tubular bowling ramp sy[illegible]

severe disability to normal human flaws, and fantasies shatter quickly. Still, I had prepared for this moment; I was wearing my bathing trunks under my pants. I found the bathroom, took off my clothes and kicked off my sneakers—I kept them tied at all times. When I came out of the bathroom, Lynn teased me about being so slow. We both laughed and hit the pool.

I don't feel completely safe in water, but I still had a great time. We spent two hours in the pool; then, it was time to get out and get dressed.

The Nightmare Begins

This was where my nightmare began. I felt a bit nervous on my way back to the bathroom to get dressed, but I knew I had everything I needed—especially my buttonhook. I could not button anything without it, and I carried it with me all the time. Everything was going fine until I got to my pants. In all my planning, I had forgotten that these pants were a bit tight-fitting and had a small button. The buttonhole was a little bit too small for the buttonhook, but after a long struggle, I finally forced it through and latched it onto the tiny button.

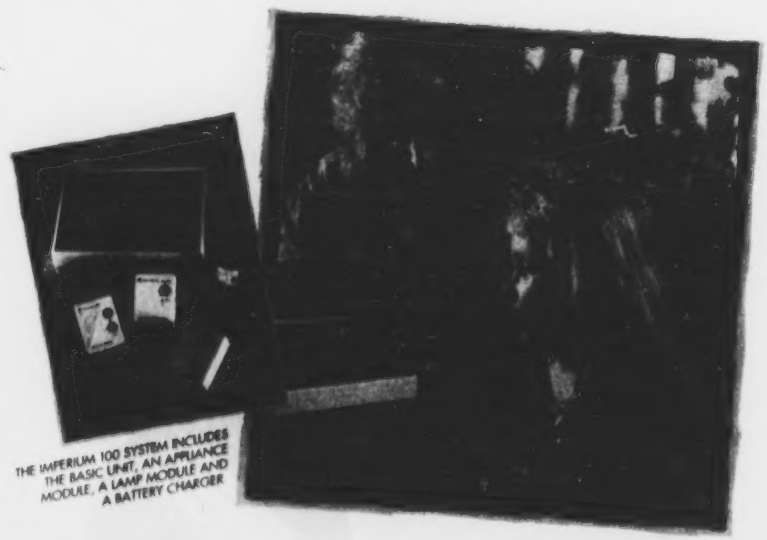
Whew! At this point, I was sweating big marbles, but I thought the worst was over. Then, I tried to pull the button through the buttonhole and discovered that the buttonhook would not budge in either direction. I could not pull the button through the hole, and because the buttonhook was so taut, I could not force it to let go of the button. I knew I would not be able to zip up my fly without buttoning my pants. To make things even worse, the buttonhook was positioned so that at first glance, it looked like I was sexually aroused.

In this condition, I could hardly walk out of the bathroom to ask for help! So I pulled and pushed and tugged on the buttonhook for what seemed like hours. I had made no progress and was starting to cry. I didn't want to do this, but it was my last option—I'd have to ask Lynn's father for help.

From Bad to Worse

Lynn was walking back and forth in front of the bathroom door. I guess she was wondering what was taking me so long. I poked my head out and asked her to go get her father. She looked at me curiously but agreed.

A few minutes later, her father came marching into the bathroom with a very stern look on his face. I showed him the problem, and he was able to help me out. Then I made my biggest mistake of the day. In a feeble attempt to humor my way out of a bad situation, I said something like, "I bet you were a little worried about me when I asked you to meet me in



THE IMPERIUM 100 SYSTEM INCLUDES THE BASIC UNIT, AN APPLIANCE MODULE, A LAMP MODULE AND A BATTERY CHARGER

Empower your child.

THE IMPERIUM 100 ENVIRONMENTAL CONTROL SYSTEM PUTS INDEPENDENCE WITHIN YOUR CHILD'S REACH

THE IMPERIUM 100 IS AN ENVIRONMENTAL CONTROL UNIT DESIGNED ESPECIALLY FOR PEOPLE WITH LIMITED MOBILITY. SIMPLE TO OPERATE, THE IMPERIUM 100 ENABLES CHILDREN TO TURN ELECTRICAL APPLIANCES ON AND OFF WITH THE TOUCH OF A SINGLE SWITCH. AND WITH THE ABILITY TO TURN LIGHTS AND RADIOS ON AND OFF, CHILDREN DO MORE THAN CONTROL THEIR OWN ENVIRONMENT – THEY REACH A HIGHER LEVEL OF INDEPENDENCE. IT'S SO SIMPLE YOUR CHILD WILL BE USING IT IN MINUTES.

➤ *AS EASY TO USE AS IT IS TO AFFORD.* PRICED TO MEET THE FINANCIAL NEEDS OF PARENTS, THE IMPERIUM 100 IS THE MOST AFFORDABLE ENVIRONMENTAL CONTROL UNIT OF ITS KIND. ITS MODULAR DESIGN AND AFFORDABLE ADD-ON COMPONENTS ALLOW FOR EASY SYSTEM EXPANSION TO MEET YOUR HOUSEHOLD'S UNIQUE NEEDS. ➤ CALL US AT 1-800-944-8002 FOR A FREE VIDEO AND BROCHURE EXPLAINING HOW THE IMPERIUM 100 SYSTEM WILL HELP YOUR CHILD BECOME MORE INDEPENDENT!

IMPERIUM™

THE POWER TO COMMAND

TELEDYNE BROWN ENGINEERING • 300 SPARKMAN DR. N.W. • HUNTSVILLE, AL 35807 • 1-800-944-8002

Circle # 120

HALF A LIFT IS *STILL* BETTER THAN WHOLE.

With maximum passenger seat maneuverability, a new easy off/on ground hugging platform, plus reliable all-electric operation.

The Crow River Industries VANGATER™ fold-in-half lift is a timeless classic. When folded it offers half a doorway of usable space for easy loading/unloading, more usable interior space, a clearer side view, and allows the front passenger seat to be almost fully reclined for maximum comfort. But we can't seem to stop trying to improve on perfection.

All-electric reliability.

The enclosed non-hydraulic, all-electric operating mechanism is cleaner and quieter than hydraulic lifts, especially in extreme temperatures. (There's also no leakage or unpleasant odor.) And our new auxiliary electric override provides emergency electrical lift power—not to mention peace of mind—when you need it most.

A flatter platform.

We've made getting on and off the VANGATER™ easier than ever with a new flatter platform that sacrifices nothing in ruggedness and reliability. And you'll find the improved side entry option and exit access great in tight parking situations!

RAPID RESPONSE LINE:
For more information and the name of your closest dealer call *today*:
1-800-488-7688

Circle # 14

CROW RIVER™
Industries Incorporated
14800 28th Avenue North
Minneapolis, MN 55447 (U.S.A.)
(In Minnesota, 612-559-1680)

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support

The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 13

At the wedding reception: *John, 32, with new wife Linda, accepts the congratulations of his aunt, Hope King.*

the bathroom." I started to giggle nervously as he stared at me, his expression unchanging. I began to hope that he had not understood a word I said.

Finally, I came out of the bathroom. Of course, by this time, I would have been happy to stay in there forever. When I emerged, everyone was very quiet. I said my good-byes and climbed back into Lynn's car. She drove me home silently. I guess we were both embarrassed—she for her parents, me for myself.

I did it! I did it!

On Monday, I went back to work. Lynn was gone, but people knew I had been to her house over the weekend. As it turned out, this marked the beginning of a change in the atmosphere. I was still the butt of some jokes, but not as many. It seemed that because someone had started a relationship with me, it became all right for others to do the same.

Another good thing came of this embarrassment. The next Saturday, I was sitting in my bedroom feeling sorry for myself. Through the open door, I could see my mother at the ironing board. She was ironing the pants that had caused me so much grief just one week ago.

Seized by a sudden impulse, I jumped up, ran into the next room and grabbed the pants. Mom was left running the iron back and forth over the bare ironing board as I slipped back into my bedroom and locked the door. I heard her walk to my door, knock on it and call my name. When I didn't respond, she left.

Three hours later, I burst out of my room yelling, "I did it! I did it!" I could now button those darn pants without using a buttonhook. To this day, I can button any pair of pants I own without assistance.

John Gray lives in North Attleboro, Massachusetts with his wife, Linda. After studying for seven years, he earned a college degree. He has recently completed a computer training program for people with severe physical disabilities and is pursuing a career in journalism.

Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Circle # 77

STROLL INTO A NEW WORLD

Not only can you take your child to places you both would like to go, our **SPECIAL NEEDS STROLLER PACK** will give your child a whole new outlook.

STROLLER Pack
A Way of Life

Call for Information
1-800-487-9652
SKAGGS & INGALLS INC.

Circle #78

Circle # 78

Don't take our word for it. Ask Mom ....

"Justin enjoys being able to see everything around him. His headrest has helped with his schoolwork since he doesn't constantly struggle to keep his head up!" **Sandy Keethler, Justin's mom**

WHITMYER BIOMECHANIX, INC.

848 Blountstown Hwy. Suite H (904) 575-5510
Tallahassee, Florida 32304 FAX (904) 576-4798

Circle # 188

- Remote hand control calls the Handi-Move to your bedside.
- Patented gripping system assures a safe, secure fit.
- Shoulder strength not needed.
- Leaves your seat unobstructed.
- Choice of overhead track or free-standing movable unit.
- Streamlined design permits lifting even where the ceiling is low.
- Rugged construction and 2-year warranty.

handi-move PATENTED
982 Route 1–Pine Island, NY 10969
(800) 724-5305

Circle # 35

497

MIC-KEY®

Skin Level Gastrostomy Feeding Kit

Additional Sizes Immediately Available !

Features . . .

- **Designed for improved cosmetic image**
- **Designed for easy placement and exchange**
- **Complete size range for Adults and Pediatric patients**
- **No obturator needed**
- **Available with:**
  - **Patented SECUR-LOCK® Extension Set**
    - **that virtually eliminates disconnects**
    - **with separate feeding and medication ports**
  - **Bolus feeding set for easy bolus feeding**
- **Superior balloon design**
  - **SHUR-FORM® balloon system assures proper inflation.**
- **Stoma measuring device**
  - **Easy to read**
  - **Provides consistent, accurate measurements.**
- **Made of clear medical grade silicone material**

MEDICAL INNOVATIONS CORPORATION
A DIVISION OF BALLARD® MEDICAL PRODUCTS

Ballard Medical Products
12050 South Lone Peak Parkway, Draper, Utah
(801) 572-6800 • Fax: (801) 572-6999

For More Information Call: 1-(800)-528-5591

U.S. Patent Nos. 4,798,592 • 4,686,901 • 4,701,163
Other U.S. patents pending and foreign patents issued and pending

Circle #167

The First Time

A father reacts to his son's first seizure.

by Robert Perretz-Rosales

PARENTING

My son, Simon, struggled through a lot in his first eight years. He didn't know how to suck and was fed through a tube until he was six months old. He didn't have the strength to lift his oversized head until he was two. At three, he still couldn't move from the spot where he was left. Only after a year of intensive home therapy did he take his first step. By eight, he was running around and things were going better. Then, out of nowhere, he had a grand mal seizure.

At first, I didn't know what was happening. He said there was a buzzing sound and wanted to know what it was. I listened intently and looked around for a fly or wasp, but I didn't see anything. Since his hearing is so acute, I assumed it was some faint motor that I couldn't hear.

A little while later, he asked again about the buzzing. I told him I didn't hear anything. Then, I asked him to come to his room for a story.

He had difficulty standing up—the kind of balance problem he'd had a few years earlier while learning to walk, but not recently. Finally, he stood and faced me. I could tell something was very wrong. He took a few drunken steps and just toppled over, not even trying to catch himself, like laundry falling to the floor.

My hands arrived in time to break the last of his fall. Most of his weight landed on his knees and face. I imagined a heart attack or stroke. Nothing ever scared me more.

I rolled his limp body over onto the mat he uses as a bed, and then it really began. I had never seen anyone have a full-blown seizure before, but as soon as his body became rigid, chin tucked in, face tensed as though a billion volts of electricity were being shot through him, I knew that my son was having a seizure. I knew that, but I was still afraid he was dying or that a part of him was going some place from which he would never return. It was all too strong, too powerful—my soft little son riveted by such force.

But I knew what it was—thank God, I knew that—so one of my selves stayed there, kneeling over him, talking soothing words to absent ears, stroking concrete. Frightening as it was, if I hadn't known, at least on some level, I don't think I could have stood it.

I kept telling myself that this would stop soon. I kept telling myself that it would end and that my son would be fine, maybe even better than before.

It continued for who knows how long, and then his eyes started blinking. His mouth started moving, making a sucking noise, over and over again. His eyes were in another universe. The blinking and noises were like some cartoon character imitating a slot machine gone haywire—over and over again.

Finally, he just laid there, and for a moment that was the worst—he seemed to fade away. Even though I knew better, I had to shake him and not let him go. I knew it was just a seizure, but couldn't let him go, just in case.

He had become too pale, too drained, too empty. I lifted his arm. It flopped. I wanted him back, all of him, just like before. And although I told myself he would be fine, I didn't know if he would be.

He rolled over then. My boy rolled over, groaned and even opened his eyes. He was fine, but so tired that he went right to sleep—a good sleep, a replenishing one with a soft pillow under his head and his favorite blue fuzzy pillow Grandpa made for him in his arms. A regular,

Six-year-old Simon enjoys a ride on Dad's shoulders.

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA

Circle # 12

Simon Perretz-Rosales, age 12.

deep sleep just like always, just like him.

My son has had several seizures since then, each pretty much the same. They continue for about two long minutes after which he is restless and squirmy for a while before he sleeps. He always wakes up fresh and ready-to-go after a few hours. The sight of his body being overpowered by a seizure is still hard to see, but now, at least, I know about that peaceful slumber ahead.

Robert Perretz-Rosales lives in Olympia, Washington with his wife, Griselda, and their two children, Simon, 13, and Sahra, 16. Robert is completing a master's degree in counseling from the Leadership Institute in Seattle. Griselda works as a family therapist.

For people with disabilities,

WE CAN

turn your computer into an open door.

A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3383 (TDD); in Canada, 1-800-465-7999.

At IBM, we can do more than you think.

IBM INDEPENDENCE SERIES

© IBM Corp. 1994. ® IBM and Independence Series are registered trademarks of International Business Machines Corporation.

Circle # 121

NEW IMPROVED

To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market maker and the [illegible] selling brand of instant food thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call (800) 333-0003.

Circle # 169

John Kemp

Growing Up With Inclusion

John Kemp, Executive Director of the United Cerebral Palsy Associations (UCPA), was interviewed by EXCEPTIONAL PARENT *in June 1994. John, who was born with multiple limb anomalies, grew up in Bismarck, North Dakota where he attended a regular public school and private Catholic schools. He graduated from Georgetown University in 1971 and Washburn University Law School in December 1973. After law school, John worked for seven years as an environmental attorney and consultant on disability-related legal issues. From 1982 to 1990, he served in a number of positions at the National Easter Seal Society. He has held his current position at UCPA since June 1990. This is the first part of our interview; part two will appear in the August 1994 issue of* EXCEPTIONAL PARENT.

PART ONE

I was born on October 10, 1949. When I was born, it was very obvious that I was missing the lower part of my arms. I did not have elbows, but the upper parts of my arms were of normal length; it's just that there was nothing at the end of the stumps. My right leg had a knee and several inches of one of the two bones below the knee with three toes on the end of that stump. My left leg ended at the knee, and I had three toes on the end of that stump.

My family has been very important to me; we are very close. I have two sisters who both are able-bodied. My older sister, Kathy, is four years older than I. My younger sister, Mary, was born eleven months after me. Three months after Mary was born, when I was 15 months old, my mother died of ovarian cancer. My dad raised us while continuing to accept jobs of greater and greater responsibility for the federal government. That meant that we moved around a bit—from Iowa, where I was born, to Minneapolis for a couple of years and then to Bismarck, North Dakota where we lived from 1952 to 1963.

I got my first set of arms when I was two. They were arms without elbows—I would slide into them like a harness over my shoulders. I got legs when I was three; then, when I was four, I got my first set of arms with elbows. That meant I could learn how to feed myself and take care of myself in the bathroom. My dad tells me he taught me to walk using a set of parallel bars in the back yard in Bismarck—just back and forth, back and forth.

School Inclusion

Early on, my dad developed the philosophy that I would live as normal a life as possible. He did not like the ideas of institutionalization or segregation. He believed that it would be best for me to stay with my family and go to regular schools. So, in 1954, when it was time for me to start kindergarten in Bismarck, he was as good an advocate as there ever has been. He told the school administrators that I would be coming and that I needed minimal assistance. He had taught me how to take care of myself in the bathroom; so they did not even have to worry about that. Basically, he just created the expectation that I was a part of the community and would attend regular schools.

My dad was as good an advocate as there ever has been. He just created the expectation that I was part of the community and would attend regular schools.

So I did. I went to kindergarten, first and second grade in a public school. I had very little assistance from the teacher—just things like taping paper down on the desktop so that it wouldn't move around when I was learning how to write. I walked five blocks to school and back in all kinds of weather.

I remember running up and down the block playing cowboys and Indians with my six-shooters on my hips, stuff like that. School was a great deal of fun. I have always done very well in school and enjoyed it. I once heard a blind individual talk about his view of schooling as a liberal education—there is the academic part, and

Now there's help for older children who have nighttime accidents.

A GUIDE TO

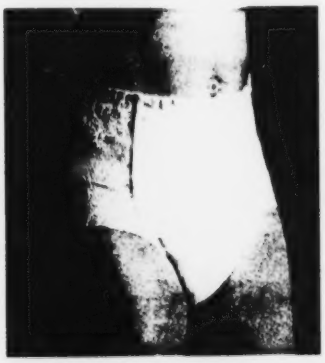
Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS

See back for valuable GoodNites $1.0 coupon

GoodNites™ keep older children dry overnight.

Disposable Absorbent Underpants

Bed-wetting is a common problem for older children.



GOODNITES Absorbent Underpants offer discreet, easy-to-use protection in two sizes to fit boys and girls 45-85 pounds.

You and your child are not alone. Between 5 and 15 percent of all older children experience nighttime accidents. That's almost 3 million children.

There are many causes of bed-wetting. Some are physical, and some are emotional. Since bed-wetting can be a sign of a more serious problem, the first step is to see your doctor or pediatrician. He or she can help you discover the cause and suggest the best treatment for your child's bed-wetting. Meanwhile, you can reduce the inconvenience of bed-wetting with protection from GOODNITES™ Absorbent Underpants.

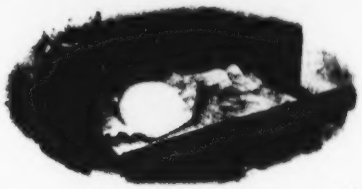
GoodNites™ Absorbent Underpants help make your life a little easier.

With GOODNITES™ Absorbent Underpants your child wakes confidently to a clean, dry bed. You and your child can sleep through the night so your day starts out easier without tension over bed-wetting or the hassle of extra laundry.

GOODNITES Absorbent Underpants look and feel like regular underwear. They can be put on and taken off just like cloth underwear which helps build self-esteem.

Look for GOODNITES Absorbent Underpants in your training pants and diaper aisle.

Your child will feel more confident with an active role to play.



Allow your child to be responsible for storing his or her own GOODNITES Absorbent Underpants

A good way to help your child feel better about bed-wetting is to put him or her in charge of GOODNITES™ Absorbent Underpants. Your child can store, put on and dispose of GOODNITES Absorbent Underpants and let you know when the supply is low. This will make your child feel positive about taking responsibility and help eliminate the helpless, passive feeling that often accompanies bed-wetting.

Why kids like GoodNites™ Absorbent Underpants.

GOODNITES™ Absorbent Underpants are specifically designed for larger children. There's nothing else like them. They're plain white with no babyish designs or colors so a child can wear them with confidence even in the daytime. GOODNITES Absorbent Underpants offer a trim, comfortable fit and are totally discreet, disappearing under pajamas to build your child's independence and confidence.

Your child will not be embarrassed by crinkling plastic noises because GOODNITES Absorbent Underpants are quiet under clothing. Children who wear GOODNITES Absorbent Underpants feel better about themselves and that makes for better mornings for everyone.

How to make bed-wetting easier to control.

- **Watch what your child drinks** *Limit liquids after dinner Drink water, not juice or soda*
- Avoid soft drinks with caffeine
- Put child in charge of his or her own GoodNites™ Absorbent Underpants
- Support and praise will help your child

GoodNites™ Absorbent Underpants are comfortable, easy to use and provide all-night protection.

Blue waistband clearly indicates back of pant

Discreet, white outer cover looks and feels like underwear and is moisture-proof

Stretchable sides provide a comfortable, snug fit

Thin, absorbent core offers all-night protection

Leak Guards stop leaks

Try them and see why only GOODNITES™ Absorbent Underpants can help you and your child to great mornings.

Pull-Ups GoodNites DISPOSABLE ABSORBENT UNDERPANTS

See back for valuable GoodNites™ $1.00 coupon.

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS

Help make great mornings.

Kimberly-Clark

Manufacturer's Coupon
Expires December 31, 1994

Save $1.00
Any Size Package
Pull-Ups GoodNites
DISPOSABLE ABSORBENT UNDERPANTS

4372

5 36000 15276 5

FREE BOOKLET!

Terms: GOODNITES™ Absorbent Underpants FREE Book Offer

"We're Dry Kids Now!" The GOODNITES™ Guide for Kids.

An illustrated booklet for children on dealing with nighttime accidents. Also an informational booklet for parents describing causes of nighttime accidents and ways to help children stay dry all night.

Please send me my **FREE "GOODNITES™ Guides to Bed-wetting"**. I am enclosing $1.00 for shipping and handling and 3 proof-of-purchase points from any GOODNITES™ Absorbent Underpants package.

3 GoodNites POINTS

1 corner of proof-of-purchase panel found on package

Mail To: GOODNITES™ Book Offer
P.O. Box 2236
Maple Plain, MN 55592

Offer expires December 31, 1994

Name _____

Address _____

City _____ State _____ Zip Code _____

506

Please help us learn more about absorbent products for older children by marking your answer to the questions below. The answers will be kept confidential and will be used in aggregate to help us better meet the needs of children like yours. You do not need to answer these questions to qualify for the free book offer. Thanks!

1. How many NIGHTS in an average week would you need an absorbent product? 0 1 2 3 4 5 6 7

2. Does your child use absorbent products to during? Yes ___ No ___

3. How many absorbent products to avoid your child's in an average 24 hour period? _____

4. Have you purchased GOODNITES™ Absorbent Underpants? Yes ___ No ___

5. How would you rate your satisfaction with GOODNITES™ Absorbent Underpants? Very satisfied ___ Satisfied ___ Neutral ___ Not very satisfied ___

6. Do you plan to buy GOODNITES™ Absorbent Underpants again? Yes ___ No ___

7. What other absorbent products does your child use? (Check as many as apply) ___ Other disposable absorbent products ___ Washable absorbent products

___ Disposable diapers ___ Disposable training pants

___ Other (please list) _____

then there's the social part where you learn to get along with everyone else. It was the social component that I think I needed and benefited from the most. Although I did fine academically, I needed to learn how to get along with and compete with able-bodied kids. I think I benefited greatly from being integrated.

I was the only kid in school with a disability until I went to high school. Actually, my dad used this fact to "sell me" to the public schools first and then, when I was in third grade, to the Catholic school I attended. He argued that not only would I benefit from an integrated education—what we would now call an "inclusive education"—but that the other kids who came in contact with me also would benefit. They would learn that I was just another kid, that I have the characteristics of disability just as they have characteristics of wearing glasses, having brown hair, having green eyes or whatever. He was one of those cultural diversity types. He has always been a very forward-thinking guy, and he was way ahead of his time.

John Kemp, 11, 1960 National Easter Seal poster child (Photo: National Easter Seal Society).

I also know that because of his commitment to my inclusion, my dad turned down some employment opportunities—and when I was about twelve or thirteen, a real promotion. That job would have brought him to Washington, DC, and he turned it down because they would not accept me into the regular school system in Montgomery County, Maryland. Today, Montgomery County is one of the leading school districts in the country in terms of inclusion and services for children with disabilities. In 1962, they were not so enlightened and my dad refused to accept a promotion that would have resulted in my placement in a segregated school system.

Catholic School

Our family is Catholic, and my dad wanted me to go to the Catholic elementary school that opened when I was in third grade. It was a block closer to our home.

Saint Anne's School let me participate in everything. For example, I got to be an altar boy. I couldn't carry things but I was the bell ringer. I'd work it out with the other altar boy; he'd do all the work and I'd ring the bell. We always managed to choreograph it and it worked out just fine.

When I got to high school, I was sitting in a freshman class when this fellow came by to talk to us about entering the priesthood. I thought that maybe that would be something that I would want to do. So I went up to him and said I would be interested. He looked at my clamps and said, "You could never be a priest because you have to have hands to touch the body and blood of Christ."

I thought, "That's a little tough. Nobody just walks up to me and gives me that kind of slap across the face!" But, that was the only time in the Catholic church that I really felt that they were discriminating against me. Otherwise, I participated in everything.

Athletics

I also got into athletics. In the summer, I played on a Little League baseball team and had a great time. They would just choose up sides, and we would get assigned to a team and be in a league for something like six weeks. I was always the last guy picked because I was the worst player, but they always let me play. I got to bat my regular turn and I got to play in the field. I don't remember if I ever made a hit or caught the ball. I just remember that I was always included. Even though they chose up sides on the basis of skill, they never denied me the opportunity to play.

When I was about 11 or 12 years old, I got to be a bat boy for the Minnesota Twins farm team in Bismarck. I loved it. In high school I was the student manager for the basketball, track and swimming

continued on page 40

507

INCLUSION

All Children Belong

Kenny is an 11-year-old boy who, at one time, attended a private, special education school 45 minutes from his home. His local school district felt that this educational setting was best for him due to the severity of his disabilities. Kenny, who has Williams syndrome, has fine motor impairment, attention deficit disorder, cognitive disabilities and perceptual disabilities. At the private school, Kenny was viewed as a child with significant deficits who progressed very slowly. His social skills were considered to be inappropriate and immature, and the consensus was that he was not "ready" for a return to his home district's programs.

Kenny's parents had a different view. They believed in his academic potential since he was acquiring reading skills rapidly. They realized that he could be an employable adult, and began to worry that his education at the special school was not preparing him for the real world. When they heard about "inclusion," they felt that he would benefit from attending his neighborhood school.

By working closely with their local district team, Kenny's parents succeeded in gaining his inclusion in a first grade classroom with all necessary supports. During the last three years, he has made remarkable progress. He earns A's and B's, has been elected to the student council and has friends among his classmates. He is happy and has progressed academically at a rate similar to that of his peers. He has been truly included.

Stories like Kenny's are at the heart of a recently-announced national project known as *All Children Belong* (ACB). Jointly operated by the National Parent Network on Disabilities (NPND) and the Statewide Parent Advocacy Network of New Jersey, and supported by the DeWitt Wallace-*Reader's Digest* Fund, ACB envisions inclusion as the future for our children. Inclusion embodies the humanistic values that are expressed in the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). It means we all count; our communities cannot be whole without all of us.

ACB activities began in October 1993 and will continue until September 1996. Currently, Parent Training and Information (PTI) centers in 42 states have committed to becoming ACB operational sites.

ACB bases its activities on principles essential to the meaningful inclusion of children with disabilities in their neighborhood schools and surrounding communities:

- Inclusion is a process, not a place, service or setting.
- Children and youth with disabilities have the right to participate in the same neighborhood schools, classrooms, extracurricular activities and community programs they would attend if they did not have a disability.
- Children and youth with disabilities should have all necessary supports to ensure successful experiences and achievement of potential.
- Children and youth with disabilities bring their inherent gifts to their schools and communities.
- Children and youth with disabilities must be afforded the dignity of risk.
- Communities should have the capacity to support participation of children and youth with disabilities in all aspects of community life.
- Children and youth with disabilities must be guaranteed their civil and educational rights as defined in Section 504 of the Rehabilitation Act of 1973, the IDEA and the ADA.
- The value system of the school and community should be based on the belief that *all* children belong.

"Cowboy" Brian Raia celebrates Halloween with other members of Mrs. Stramara's first grade class in Edison, New Jersey.

Project Design

Via a train-the-trainer parent curriculum, ACB project staff will train trainers from each participating Parent Training and Information (PTI) center throughout the country. These PTI trainers will train and support parents within each state on the benefits of inclusion in school and community life. From this pool of trained parents or through other means, the PTI trainers will recruit 15 parents (five per trainer) to establish and serve as liaisons to Community Inclusion Action Teams (CIATs) in their own communities.

These teams bring all of the key stakeholders together—parents, educators and community leaders—to promote school-family-community partnerships. CIATs will support the inclusion of children and youth with disabilities through creative problem-solving and collaborative team building.

508

REACH FOR THE STARS

94 ABILITIES EXPO Chicago

The #1 Show of Products and Services for People with Disabilities

Opportunities to try and buy on the Show floor

One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-Wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

Longest running Show of its kind in the U.S.

Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO near you:

ABILITIES EXPO
Chicago, IL
Rosemont Convention Center
August 12–14, 1994

For more information on attending please call 203/256-4700, X131 or write: Abilities Expo, 363 Reef Road, P.O. Box 915, Fairfield, CT 06430-0915

Sponsors:

City of Chicago
Richard M. Daley, Mayor
Mayor's Office for
People with Disabilities
Lawrence J. Gorski, Director

Easter Seal
Society of
Metropolitan
Chicago

SAVE ONE DOLLAR • SAVE ONE DOLLAR

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. *Name and address must be completed to validate coupon.*

Name _____

Address _____

City _____ ***State*** _____ ***Zip*** _____

Telephone (____) _____ – _____ **IL94/D**

ABILITIES EXPO — *Chicago* — Produced and Managed by Expocon Management Associates, Inc. in conjunction with RCW Productions Inc. — *Chicago* — ABILITIES EXPO

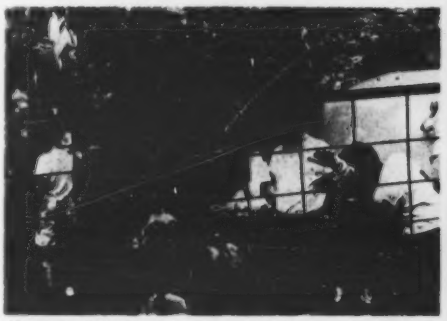
Additionally, coalitions or networks that are currently working to promote inclusion within states can operate as CIATs. The parent liaison can provide support to such teams or coalitions just as he or she would to a newly-formed team.

Project Materials

All Children Belong materials consist of a train-the-trainer curriculum, community inclusion action kits, a related readings manual, an electronic resource database and videos.

• *Train-the-Trainer Curriculum:* The train-the-trainer parent curriculum corresponds to four phases of planning for children and youth with disabilities—from awareness of inclusion and individualizing supports, through statewide efforts to promote system change. The materials are consistent with the four phases of the evolvement of inclusion that have been identified through research and practical experience.

• *Community Inclusion Action Kit:* The second major element of *All Children Belong* is the "community inclusion action kit" which serves as a starting point for local CIATs, existing state or community coalitions, networks or collaboratives. The kit provides the team with an introduction to the project and a brief overview of inclusion, its benefits and its implementation. The kit includes community self-assessment tools to assist the team in determining what changes, if any, are necessary to improve their project.



Kate Cuthbertson (foreground) enjoys a class field trip to a petting zoo.

• *Related Readings Manual:* Each CIAT will also have access to a related readings manual that will include the most current, state-of-the-art writings on inclusion. This manual will be available through the team's parent liaison.

ACB MATERIALS

Train-the-Trainer Manual (160 pp)	$25.00
Related Readings (325 pp)	40.00
Teleconference Video Tape	28.00
Teleconference Book (150 pp)	15.00
Brochure	Free

Order these materials from NPND, 1600 Prince Street, #115, Alexandria, VA 22314.

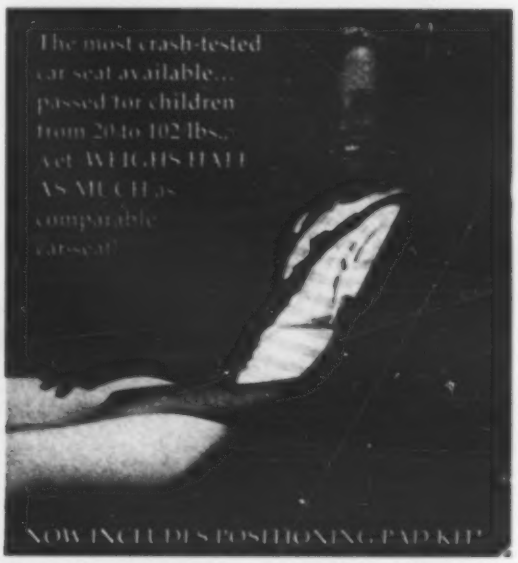
ACB PROJECT STAFF

Patricia McGill Smith, *Director*
Diana Cuthbertson, *Co-Director*
Larry Searcy, *Assistant Director*
Gaye Hasslinger, *National Trainer*
Orah Raia, *National Trainer*

*Super **Light**, Super **Strong**, Super **Safe**, Super **Simple**...the Columbia Car Seat has been the #1 choice since 1986* Thousands of Columbia Car Seats are now in use, and we have received some amazing crash stories. One grateful father in Louisiana sent a picture of his badly crumpled van and said, "My 4-year-old son escaped without a scratch, did not even break his glasses." One mother in Colorado wrote, "Thank you for making such a wonderful car seat! I really like how comfortable [my son] is in it. On Dec. 5, 1991, we were hit extremely hard on the passenger side. My 6-year-old son, a healthy 65 pounds, was not hurt at all because your car seat held him so securely."

Our years of *real world* experience give you peace of mind knowing your child is comfortable and secure in our seat!

PLUS it's lightweight, easy to use, good-looking and easy to care for!



Ask for our FREE Full Color Catalog of convenient, helpful products

The Columbia Car Seat is your best value!

- The LIGHTEST special car seat–easy to handle!
- Fits easily into ALL vehicles, no matter how compact!
- EXCEEDS all Federal safety standards!
- Approved for car, school bus and even airplane travel!
- Fits your choice of 4 stroller bases!

MEDICAL MFG. CORP. (800) 454-6612 Dept CL, P.O. Box 633 Pacific Palisades, CA 90272

Circle # 11

510

• *Resource Database:* As the project evolves, examples of leadership, innovation and insight will be recorded in an electronic database. This information will be available to all ACB sites. It will be disseminated through a variety of channels including print material and the telephone.

Nine-year-old Brian Raia (red helmet) participates in "Buddy Ball" baseball in his home community of Edison, New Jersey.

Project Activities

After preparing training materials and holding an orientation meeting, the first NPND national teleconference was held on March 9, 1994. The teleconference was "downlinked," or shown simultaneously, at 22 sites. It involved over 250 participants. The three-hour interactive teleconference included live and pre-recorded participation by Judith Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education; Tom Hehir, Director of the Office of Special Education Programs, U.S. Department of Education; Bob Williams, Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services; Martha Fields, Executive Director, National Association of State Directors of Special Education; parents of children with disabilities and the ACB national staff. Questions from participants provided a healthy "reality check" for teleconference presenters.

The ACB national teleconference is now available on a three-hour video tape. Shortened versions of the teleconference will soon be available for presentations at conferences and training sessions. As other video activities occur, tapes of these events will also be made available.

Following the teleconference, the ACB national trainers held on-site training for the Technical Assistance for the Parents' Project (TAPP) southern region in Hot Springs, Arkansas and for the midwest region in Milwaukee, Wisconsin. Next spring, training sessions will be held in west and northeast regions.

In future months, articles in *Exceptional Parent* will update the activities of the ACB operational sites as the successful inclusion of children with disabilities in their schools and communities picks up momentum.

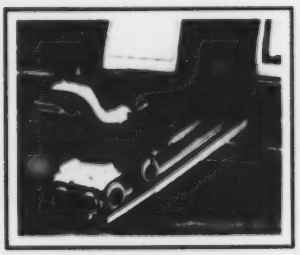
For more information about ACB, please contact Orah Raia or Gaye Hasslinger at (908) 654-0980 or Larry Searcy at (703) 684-6763, voice/TTY.

EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

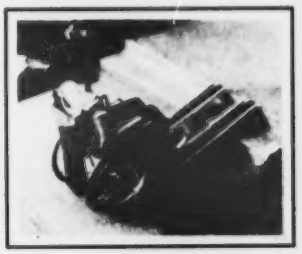
Rollup/3' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty



Vanramp R2000 7' or R6000 10'

Look for this Seal of Quality



R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle # 40

ADJUSTEASE = CLEANING SOLUTION
SY, IT'S CHILD'S PLAY!

Safe, wet fun in the shower and bath—and it goes to the beach or pool, too!
AdjustEase Washchair's your sensible back- and back-saver!

An AccessAble, successful bathtub replacement! Good-looking and barrier-free, **Accessshower's** an easy to do 1-day, no-plumber project!

It's a safe investment—you can even take it with you when you move!

ORDER YOUR ACCESSHOWER™ SYSTEM "CLEANING SOLUTION" BY AUGUST 30 TO CLEAN UP 2 MORE WAYS:

❶ SAVE 40% (up to $365!) ON YOUR CHILD'S ADJUSTEASE™ WASHCHAIR!

— PLUS —

❷ GET THE AMAZINGLY ADAPTIVE ORALGIENE™ FAMILY ORAL-CARE SYSTEM FOR ONLY $59.99! (regularly $89.99!)

AccessAble™
ENVIRONMENTS + PRODUCTS
FOR EVERY BODY!

1 800 285 2525

YES, WE CAN FILL 3rd PARTY PURCHASES THROUGH LOCAL DEALERS! JUST CALL US FIRST!

Circle # 9

Circle #71

Chairman of the Board.

That's my son Jedidiah. He's the reason I started Special Designs Inc. You see, as a parent of a disabled child, I had a lot of trouble finding furniture to fit my son's special needs. Furniture that's durable and sturdy, easy to adjust and easy to take along to a restaurant or to Grandma's. Furniture that looks like it belongs in a home--not in a hospital.

Finally, I got tired of looking and made it myself. Then it occurred to me--maybe other parents have the same needs. That's how it all began. If you want to know more about our full line of furniture for disabled children, call us at the number below, or write for a free catalog.

What's it like working for Jed? Easy. I've never had a more lovable boss.

-Peter Quense

SPECIAL DESIGNS, inc
CUSTOM EQUIPMENT FOR SPECIAL KIDS

(908) 464-8825
P.O. Box 130, Gillette, NJ 07933

Circle # 71

ROLE MODELS *continued from page 35*

teams. I earned seven varsity letters doing that. That was my vicarious way of being a jock and hanging out with the guys.

Small Town Life

I think that one reason my inclusion worked was because I lived in a small town. In Bismarck, everybody knew each other. They couldn't imagine John Kemp's son, Johnny, not going to school with the same kids he played with every summer. It was just unthinkable. They just couldn't imagine that they would know somebody that they would then reject. There is a lot to be said for small towns and rural America where they just accept you for the way you are. In big cities, you're a number; you get to be a disability, not a person. You are slotted into a category and nobody connects with you as an individual.

Of course, I still got teased a lot. One day, I came home crying that these kids had been making fun of me. They said I had wooden arms and wooden legs *and* a wooden head—which probably isn't too far off the mark!

My dad said, "Well, those kids have a handicap, too." He said something that folks with disabilities today believe in very strongly. He told me that I might have a disability, but other people who don't accept me have a handicap. A handicap is something external to me that interferes with my freedom to be a part of my community. A curb without a curb-cut is a handicap to someone in a wheelchair. A shiny, round doorknob is a handicap to someone who has clamps and hooks. People's negative stereotypical thinking about individuals with disabilities is a handicap to our acceptance. That was the first time someone had lifted the burden of "handicappism" off of me. I got teased, but my dad put it into perspective—"it's their problem not yours."

512

Confidence, Independence, Success...

The Crotched Mountain Rehabilitation Center and Preparatory School offers innovative academic, therapeutic, residential, and medical services designed to maximize the educational potential of physically and developmentally challenged children and young adults with:

- Head Injury
- Cerebral Palsy
- Spina Bifida
- Autism
- Down's Syndrome
- Developmental, Behavioral, Emotional and Neurological Disorders
- Fetal Substance Exposure

The CMRC program includes:

- Fully Accredited Preparatory School Curriculum
- Modern Residential Group Homes
- Licensed Skilled Nursing Facility
- Accessible, State-of-the-Art Library
- Total Communications Center
- Fully Adaptive and Accessible Sports Facility
- Comprehensive Transition Services

For more information on these services or those of our subsidiaries, please contact our Admissions Officer, Debra Flanders at (603) 547-3311, ext. 235.

CROTCHED MOUNTAIN

A subsidiary of the Crotched Mountain Foundation
1 Verney Drive, Greenfield, NH 03047, (603) 547-3311

Circle #17

Not For A Nickel and a Dime

by David M. Cameron

The lights... the lights are the thing. And the spinning. Sound and colors attract as well, but it's mainly the lights and the spinning. A ticket costs 50 cents—half a dollar for a few minutes riding the carousel, spinning with the lights and circling within the rotating wheel. Fifty cents buys little these days, so to spend it on a few minutes of merciful delight is well worth it—especially since for those few minutes, Will's squeals of glee sound no different than the squeals of the 10 or 15 other children. His gap-toothed smile is not out of place. His inability to speak makes no difference. He is a four-year-old where a four-year-old should be.

David Cameron joins Will for a ride on the carousel.

I go to the ticket booth. A kindly woman puts her sandwich down and wipes mayonnaise from her smile. "One," I say, holding two quarters with one hand and Will with the other. She tears off a ticket and directs me around the railing to the line where other would-be jockeys wait.

As we leave the ticket booth, Will does his "Will Thing"—part squeal, part dance, part earnest response to a stimulus I don't share. I don't even think about it, it's such a part of who Will is and who I am in relation to him. But the kindly ticket-taker notices. In a conspiratorial hush, she whispers, "Is he handicapped?"

God, yes! God, no! God knows. "Yes," I conspire back, wondering why she has to ask and why I feel compelled to answer.

"Then, his ticket is only 35 cents. Handicapped children get a discount."

Don't get me wrong. There is a place for discounts, a need for parents with financial burdens to be able to lay some of those burdens down. But the label is costly, too.

For the few minutes of a carousel ride, if Will can be happy, if he can be simply one child among others, if he can spend an instant without being judged according to his deficits, then I gladly forego his discount. I would not trade those moments for a hundred dollars, certainly not for a nickel and a dime.

Will Cameron rides the carousel in Greensboro, North Carolina where he lives with his six-year-old sister, Katie, and parents, David and Kathryn. Kathryn is associate pastor at First Presbyterian Church, Greensboro; David is a Presbyterian pastor and therapist at the Presbyterian Counseling Center. Will, who has autism, is learning to communicate through sign language and other methods. When not in school, Will enjoys his weekly gymnastics lesson, backyard tree house, hula hoop and Big Wheel.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

Circle #18

Honor Thy Son

It started out as an adventure, but turned into a love story

Like all good adventures, mine started late one night. Of course, it was stormy. I was awakened by my wife.

"It's time," Michele said.

"How do you know?" I asked.

"My water broke."

"All right," I answered. "Remember what we learned in our Lamaze class. Don't panic. Just lie there and wait."

"For what?"

A moment later, it hit me. I leapt to my feet, panicked. "Come on! Let's go. The baby's on its way!"

Michele was already in her robe, bag in hand. We hurried to the car. The rain was gone. So were the clouds. Left was a huge full moon. All I could think of was the pull of the moon on tides and babies.

Lou Shaw with 10-year-old Hillary.

It was 4:30 a.m. Three hours later, Hillary was born.

Ten hours later, we learned that Hillary had Down syndrome.

Twelve hours later, I was drunk.

Twenty-four hours later, Michele was dealing with two infants, Hillary and me.

Twenty-nine hours later, I had grown up enough to agree that, despite the doctor's dire warnings, we would bring Hillary home.

Ten days later, during Hillary's first early intervention class, I had grown up enough to be grateful for our decision.

The Adventure Comes Full Circle

Five years later, I wrote and produced an episode on *The Fall Guy* television series that involved a 10-year-old boy with Down syndrome. I cast a 10-year-old boy with Down syndrome, Jason Kingsley, to play the part—47 pages of dialogue. The show was a critical and ratings success.

Ten years later, my adventure has come full circle with *Honor Thy Son*, a novel I have written dealing with a 21-year-old young man who has Down syndrome.

When I wrote the script for the television show, I was resolved to depict a boy with Down syndrome who was capable of following his dream with the same determination as any other child. Likewise, in the novel, I was steadfast in my intent to show a young man, JJ, aspiring and already building toward a full and productive adult life. Through the character of JJ, I wanted to convey that a person with Down syndrome does not need to be pitied or patronized. What he needs—like everyone else—is acceptance, understanding, love and, above all else, the right to be what he wants to be in the best way he can.

I have always felt an empathy for parents who are deeply troubled at the thought of raising a child with a disability. When such a baby is born, life-long expectations are often shattered. I wanted the character of JJ's father to be a man who, feeling bitterly betrayed and unable to cope with what seemed to him to be a catastrophe, lived in extreme anger and denial. To heighten these emotions, I chose to lock father and son together in a mystery/thriller.

Acceptance and Bonding

JJ is framed for a murder. His father, who deserted him and his mother immediately after his birth, soon finds himself a fugitive along with the son he has never been able to accept. Through their shared

ordeal and on-going conflict, the father struggles out of the morass of denial. With grief, he buries the "remarkable, highly intelligent and gifted" son of his shattered expectations.

At last, the father becomes able to see his son as a unique individual. This long-belated acceptance enables them to bond.

You see, to my surprise, my adventure turned out to be a love story.

—Lou Shaw

Lou Shaw is the creator of QUINCY *and has written for or produced the television shows* MCCLOUD, COLUMBO, MAUDE, *the* SMOTHERS BROTHERS *and* THE FALL GUY. *He won an Edgar award—the mystery writers' equivalent of the Oscar—for* QUINCY. *He also won two Media Access Awards and numerous other honors for the episode of* THE FALL GUY *that included the character of a 10-year-boy with Down syndrome and cast a 10-year-old boy with Down syndrome to play the part. Lou lives in Los Angeles with his family.*

***From* HONOR THY SON...**

... How could a love that seemed so right go wrong?

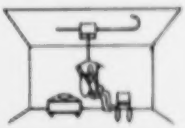
Jack was struggling to stay together. The inner claustrophobia had whipped him into a frenzied panic. "I was there and you still insist you did nothing. That means someone framed you. Why? Tell me! Why would someone bother framing you? You're not that important to anybody!"

JJ could only stare at him tearfully.

"Think! Why would someone frame you?" As JJ shrugged, "Come on. Think about it! Why? Answer! You're not that slow!"

Slow. The word flew around Jack's brain, darted through his body, went back to his brain, but could find no further escape. Jack took a long swig of scotch. Choked. Nearly threw up. *Slow*. Jack knew the statistics. A great percentage of the prisoners on death row were retarded. *Slow*. Who could be a better patsy!

Mystery lovers will enjoy* HONOR THY SON. *In addition to being an exciting, fast-paced thriller, the book will have special meaning for many readers of* EXCEPTIONAL PARENT. HONOR THY SON *is available through* EXCEPTIONAL PARENT LIBRARY, *(800) 535-1910 ($12.95, paperback).



Barrier Free Lifts

BARRIER FREE CEILING LIFTS ARE

- **Used independently!**
  Most physically challenged people can transfer themselves unassisted.
- **Air tube controlled!**
  No electricity to the user!
  No chance of being shocked!
  Can operate while in water!
- **Multi-directional!**
  Vertical & horizontal motion at the push of a button.
- **Battery operated & no maintenance!**
  Batteries are automatically recharged each time the lift is used.

Helping You Achieve Greater Mobility

Barrier Free Lifts, Inc.
P.O. Box 4163 • Manassas, VA 22110
(703) 361-6531 • FAX (703) 361-7861
1-800-582-8732

Circle # 217

Disability Really Isn't That Romantic

by Elaine Greenbaum

With imaginative public awareness campaigns, we advocates have convinced many important people that disabilities don't matter as much as rights, attitudes and accessibility. Stories, and the words we use to tell them, seem to matter more than IQs or difficulties in walking, talking, hearing or seeing.

People with "differing abilities," which seems to be the new preferred usage, do not "suffer" nor are they "afflicted." Cute children "just happen to have" Down syndrome or spina bifida or cerebral palsy. Adults, who may be physically or mentally "challenged," will overcome, get jobs and live "as independently as possible."

The medical model of disability, which focused on deficits and conditions that needed to be treated and fixed, has been rejected. Now, the major questions about disability are addressed from the more romantic view of the civil rights model. The speeches and statements at the signing of the 1990 Americans with Disabilities Act (ADA) made us all feel so very good. But no matter how well-written the stories, no matter how cute the kids, no matter how strongly we accentuate the positives with euphemisms, having a disability is not that romantic.

[Above] ***"Treat him normally"****—One-year-old Nate shares a laugh with Mom.*

Nate, holding balloons, celebrates his graduation from Montessori School.

Romance Versus Reality

Twenty years ago, we were thrilled and relieved when professionals told us to treat our newborn son with Down syndrome "normally." When Nate thrived in a regular Montessori preschool, we were delighted. We were convinced of the benefits he would reap from an inclusive education. But the conviction that his disability did not matter began to weaken somewhat as reading, writing and arithmetic became more important than juice pouring, circle time and creative dramatics.

Inclusion in a regular middle school certainly was tougher. Regular-education teachers found it difficult to adapt curricula. And, in an atmosphere where simply wearing the wrong brand of jeans is grounds for exclusion, Nate's peers had a hard time befriending someone with an extra chromosome.

But life goes on, and partial inclusion in a regular high school has worked well. I think a major reason for this success has been the use of "reverse mainstreaming" in which the most self-assured regular-education students come into our son's self-contained, special-education classroom. Zealots might argue that bringing regular-education students into a self-contained classroom is "second best" and philosophically unacceptable. In their view, "best" would be defined as the elimination of all separate classrooms and special education. I am not so sure.

The Uncertain World of Work

What I am sure of is that the years after high school will be less romantic than challenging. The romance of disabilities turns on words that stress similarities rather than differences. But the differences are nonetheless real. During this, Nate's last year of high school, we do not worry about drinking and driving, SAT scores or college admissions. Nate does not drive, nor do most of his close friends. And instead of thinking about post-secondary education, we are agonizing about the job market.

For our son and millions of other young adults with disabilities, the real world after high school graduation offers only a small chance at complete economic independence. Despite the occasional success story and the rhetoric about ADA, employment and earnings statistics for persons with disabilities are abysmal. Fewer than half of all working-age adults with disabilities are employed.

Nearly seven million adults with disabilities receive income support from the government. Eligibility for monthly checks from Supplemental Security Income (SSI) or Disability Insurance (DI) is viewed by many as

Nate Greenbaum, age 20

a right. In mid-1992, the monthly check for an individual on SSI was about $400; the check for an individual on DI was about $600. Both programs stop providing income support when an individual consistently earns $500 or more per month.

Since both public income support programs are linked to health insurance (Medicaid and Medicare), the certainty of a $400–600 monthly government check with health benefits dominates most decisions about work. Only the person with a really strong work ethic will choose the uncertain world of work over a monthly check from the government that includes health care coverage.

In the romance and emotion surrounding our embrace of the civil rights model and ADA, we advocates have ignored important economic lessons. Simple mandates have never produced enough high-paying jobs to lift large numbers of individuals out of poverty. Moreover, since many of the working poor lack health insurance, the lure of programs like DI and SSI with their link to medical insurance is easy to understand.

While the work disincentives for mothers on welfare are widely recognized, almost no one worries

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

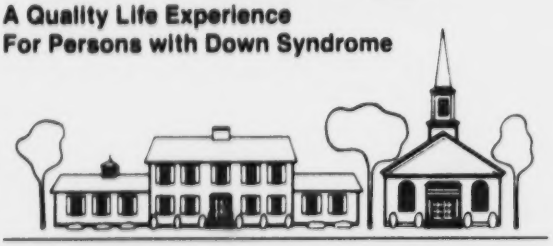
The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 66

Pathfinder Village

A Quality Life Experience For Persons with Down Syndrome



In this picturesque colonial village, located in scenic central New York State, life is full of wholesome activities and rewarding opportunities. Residents with Down Syndrome experience the joy and personal satisfaction of learning, working, and participating in a vital, dynamic community. Our year-round, co-ed program includes education, recreation, and employment opportunities plus the chance to live life to the fullest. *Call us today.*

R.R. #1, Box 32-A, Edmeston, NY 13335
Telephone (607) 965-8377

Circle # 161

TRIAID
REHABILITATION PRODUCTS

Picture Of Fun!

The best Europe has to offer at American prices. Three different styles in various sizes for all ages. Call or send for our new color catalog.

VISA-MasterCard Now Available
CALL TOLL FREE 1-800-306-6777
P.O. Box 1364 Cumberland, Maryland 21502 • 301-759-3525
Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle # 82

about similar disincentives for persons with disabilities. And when welfare reformers require that all "able-bodied" persons work, the implication is that persons with disabilities may not have to. Policy debates about workfare and health care reform tend to ignore the way that current policies work to erode the work ethic of persons with disabilities.

We Want our Son to Work

We worry. We want our son to work. Employers at all three of his part-time jobs have commented upon his good work ethic. As he graduates, he has developed certain competencies that should serve him well as an employee. His disabilities do not prohibit work; they just make it much more difficult for him to earn much more than $500 per month for the next few years.

People with disabilities are not typically viewed as welfare cases. But most do not work. The rhetoric surrounding ADA suggested that most adults with disabilities could and would work once discrimination and other barriers were removed. If it turns out that most could work but don't, the nation's reservoir of good will for person with disabilities is sure to leak away no matter how many romantic stories we tell. If it turns out that most cannot work, then the ADA is a fairy tale.

Elaine Greenbaum is co-chair of the Adult Issues Committee of the National Association for Down Syndrome (708/325-9112) and serves as a patient services facilitator at the Adult Down Syndrome Center of Lutheran General Hospital in Park Ridge, Illinois. She lives with her husband, son and daughter in suburban Chicago.

Nate graduated from high school on June 9, 1993. In August 1993, he started what his parents thought would be the perfect job—working in food service at his alma mater. The job lasted only six weeks. Nate had trained in that position for two years, but when his employer had to pay him minimum wage, it turned out that Nate worked too slowly to be a cost-effective employee. The next job he landed, folding laundry at Northwestern University's executive training center, has worked out much better.

For calendar year 1993, Nate opened an IRA and received a full refund of all federal income tax deducted from his paychecks; he paid $110 in state income tax. He spent some of his earnings on a California vacation and dreams of an acting career in Hollywood.

A.S.K.

About Your Child's Future

You have questions about your special child's future? The Association for Special Kids has trained representatives who can help answer these questions.

- **Housing**
- **Health Care**
- **Guardianship**
- **Government Benefits**
- **Finances**

A.S.K. Has The Answers!

The Association for Special Kids is a unique financial planning organization exclusively dedicated to helping parents of children with disabilities protect their child's future. Under the guidance of our Executive Director, Dr. Nita Savader, our counselors work with you as well as a network of qualified attorneys and accountants to set your plan into action. The Association for Special Kids charges no fees for its services. After all, most of our counselors are parents just like you.

For more information concerning our services, refer to the circle # below on the Business Reply Card in the back of this issue.

If you still have questions about your child's future, ask them! The Association for Special Kids will help you find the answers.

Association for Special Kids,™ Inc.

A unique financial planning organization for parents of children with disabilities.

A.S.K.
107 W. Hill Street
Baltimore, MD 21230
1-800-832-0467

Circle # 216

520

SAVING THE WORLD STARTS HERE

Right now your baby seems safe and secure in your cozy environment. But outside lies dangers that can swallow, a breath or a touch away. Hazardous chemicals in your water. Toxins in your workplace. Drugs. Pesticides. Paint fumes. Household cleaners. Radiation. Lead. Mercury. Dioxin. Environmental hazards that can limit your baby's chances before your child is born.

Over 600,000 children are born with birth defects each year in our nation. That's why we started the National Environmental Birth Defects Registry to find out why so many children are born today with birth defects, learning and attention problems, and other developmental disabilities. The more we know about the causes of children with birth defects, the better we can prevent them and support

Association of Birth Defect Children, Inc.
because every birth defect has a cause

NAME _____

ADDRESS _____

CITY/STATE/ZIP _____

☐ NUMBER OF CHILDREN YOU HAVE WITH DISABILITIES.

☑ 0853 DURING THE COMBINED FEDERAL CAMPAIGN IN YOUR WORKPLACE.

521

Circle # 2[illegible]

Association of Birth Defect Children, Inc.
827 Irma Street
Orlando, FL 32803

ASK THE DOCTOR

by David Hirsch, M.D

Questions about incontinence

Q I know that my child has a disability, but I believe he can be potty trained. How much longer than average will it take and are there any tricks that will help?

A First of all, children with or without disabilities potty train at different ages depending on their physical and developmental maturity. Normally, bowel control is achieved before bladder control. When a child is developmentally ready, bowel training can begin. For the average child without disabilities, this is usually about age two.

Before potty training can begin, the child must be willing and able to sit with feet touching the ground and with good balance—a problem for some children with certain disabilities. The child also must be able to understand what his parents expect with regard to using the potty.

Children with disabilities—physical, intellectual or both—typically take longer to potty train. Regardless of the child's disability, it is important to go at his or her own rate. Rushing the process inevitably results in *delaying* the training. A reasonable goal for many children with disabilities is for them to be trained by the time they enter grade school. In studies of individual children and young adults with mental retardation, approximately 70 percent had bowel control by age seven. Full bladder control occurred by the same age in approximately 60 percent.

Bowel control: The use of incentives (bribes) and "tripping" (taking the child to and placing the child on the potty at regular intervals) are good techniques to use in bowel training. Timing is also important. The best time to take the child to the potty is after a meal; this takes advantage of the reflex that encourages a bowel movement after eating. The ultimate goal is to teach the child to empty his bowels daily at a regular time.

Some children with disabilities can never be bowel trained because they do not have, nor can they develop the necessary control of their external anal sphincter. This is a physical limitation that has nothing to do with a child's intellectual abilities or motivation.

Bladder control: Urinary continence is another area of concern in many children with developmental disabilities, although often not as pressing as bowel control. As noted above, approximately 60 percent of children with mental retardation, who may or may not have other disabilities, achieve bladder control by age seven.

Bowel and bladder control are often related in that a child who is chronically constipated may have more difficulty with bladder control. Overnight bladder control is typically achieved at later ages for children with disabilities, especially those who are very sound sleepers.

Q My eight-year-old has static encephalopathy and is unable to eat. She is on gastrostomy tube feedings and is incontinent. Her stools are either very loose or very hard. This seems to make her uncomfortable.

A Children who are tube fed usually cannot regulate their intake of enteral preparations (special formulas fed through a tube directly into the stomach or small bowel) and "free" water (additional water that is not part of the enteral preparation). This, along with the fact that many children on tube feedings are not as active as their peers, may lead to inconsistency in bowel movements.

If chronic constipation or diarrhea is a problem, your child's pediatrician may have to make changes in her enteral formula. Most often, however, relatively simple changes will help. Additional fiber will help mild constipation or excessively loose stools. Stool softeners, many of which are available over the counter, can help mild, intermittent constipation as long as they are used with additional free water. Also, additional water needs to be given to a child during hot or dry weather.

It is best not to allow constipation or very firm stools to continue over a long period of time because it will become more difficult to control.

It is relatively common for parents to complain of "diarrhea" in a child who actually has severe constipation. A severely constipated child may appear to have diarrhea because only very loose stool can be expelled around the very hard or impacted stool in the lower part of the large bowel. It is important for parents and their health care provider to discuss this distinction so that the proper therapy can be recommended.

David Hirsch, M.D., a board-certified pediatrician, is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses. He is a member of the Section on Neurology and the Section on Developmental Disabilities of the American Academy of Pediatrics. He is affiliated with four hospitals in the Phoenix area—Phoenix Baptist Hospital, Phoenix Children's Hospital, Good Samaritan Hospital and St. Joseph's Hospital. He is a member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. He is married and has two children.

522

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

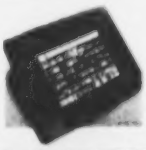
Circle # 86

You Asked DynaVox To Do Even More...

"I want to spell and talk faster."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox™ augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at **1-800-344-1778.**



We Hear You.

TECHNOLOGY INC.

Circle # 58

Richer Life **FLEXACISER**

PERFECT SOLUTION
- Multiple Sclerosis
- Stroke-Head Injury
- Spinal Injury
- Cerebral Palsy
- Muscular Dystrophy

HELPS ELIMINATE
- Poor Circulation
- Spasticity
- Muscle Atrophy
- Swelling Ankles
- Stiff Joints

High Quality Electric Motor with Speed Control

(800) 869-0862 • (310) 693-6372

Richer Life, 8131 Allport Ave., Santa Fe Springs, CA 90670

Circle # 214

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: **CRI**
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle # 162

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle # 75

"MAXIMIZING INDIVIDUAL POTENTIAL"

- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.

- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae,
Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710

CHILDREN'S CARE HOSPITAL & SCHOOL

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1000 children with disabilities and their families each year. CCHS offers individualized, family-centered programs through day school, outpatient, outreach, or residential services.

Contact: Nathan Anderson
Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840 or (800) 584-9294

Annandale Village

Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.

- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

Youth CONNECTIONS

The National Center
for Youth with Disabilities

More than 50 youth and young adults with disabilities, parents, educators, health professionals, public health and human service providers and policymakers met in early June at a working conference, *Smoothing the Course of Transition for Adolescents with Chronic Illness and Disability*, sponsored by the Division of General Pediatrics and Adolescent Health at the University of Minnesota, with the National Center for Youth with Disabilities & The Konopka Institute.

Robert Wm. Blum, M.D., Ph.D., and Colleen Wieck, Ph.D., presented the keynote, "Charting the Course of Transition." Dr. Blum facilitated a discussion among three young adults with disabilities. Here is a summary of the presentations. A monograph of the proceedings will be available later in the year.

Transition for Adolescents:

Charting the Course

The good news is, young people with disabilities are living and thriving. The challenge families and professionals face is guiding them through adolescence into adulthood.

"We are faced with a significant number of young people who are maturing into adulthood—crossing almost all conditions that were historically fatal in childhood. Now we are facing the realities of what we as professionals do to meet the needs of these populations of young people in ways that can foster successful adult functioning." Dr. Blum goes on to explain what teens with disabilities share with teenagers in general: Their body image is not more distorted; their emotional well-being is not significantly worse off; there is no significant difference in sexual activity.

None of this information is necessarily comforting. Many American adolescents have a pretty distorted sense of self. And, according to Blum, one in six or seven U.S. teens has significant emotional illness.

While some adults are surprised that teenagers with chronic illness or disability are sexually active like their peers, teens with disabilities are less likely to receive any meaningful sexual health education or information than other teens.

So while adolescents with chronic conditions share the same risks as their peers, their conditions can place them at additional risk.

It turns out, however, that teens with the least visible disabilities may be at the greatest risk of having significant emotional problems. "Often they try to 'pass' as not having a disability, but the price is living a lie," Blum says.

It's actually easier for those with visible disabilities. Tom Strax, a physician in New Jersey with cerebral palsy, says: "Every time I looked in the mirror from the day I grew up, I knew what I had. You can't deny it. You work it through." Coming to terms with one's physical condition within the context of one's life is clearly related to positive outcomes.

While facing a fatal prognosis is challenging, those young people who live with continual uncertainty also pay an exceptionally high price. The young person with epilepsy never knows

Charting the Course
Turn to page 56

Coming to terms with one's physical condition within the context of one's life is clearly related to positive outcomes.

525

The goal of *Youth Connections* is easy to state, a little more complicated to achieve. All of us at the National Center for Youth with Disabilities (NCYD) want to help young people with disabilities, their parents and their families and friends see what the future can be. But, when you consider how little we really do know about the future for people with chronic conditions, that's a pretty tall order. One thing is for certain: children born with, or acquiring chronic conditions or disabilities, are living into adulthood. Twenty years ago, the life expectancy for a child with Spina Bifida was under 10 years of age; today, the average age of survival for children with SB in the United States is 26 years of age. And survival beyond age 21 is expected for most childhood conditions: spina bifida, cerebral palsy, diabetes and even leukemia.

"I feel like I am a pioneer," a 25-year old young man with CP explained. And he is. We don't know what the future holds. No one has lived that long with these conditions. We are pioneers together and we need to teach each other about what the future holds.

At its best, *Youth Connections* should showcase the young people and programs that are leading the way. You won't read stories about extraordinary teenagers who are running marathons or climbing Mt. Everest. Rather, we hope to bring stories of "ordinary" kids making their way into work, college and careers. In this issue:

- Three young people identify some of the issues they dealt with as they became young adults.
- A high school sophomore, who understands discrimination all too well, talks about a program for teens with mental retardation at her high school.

Nothing has engaged my imagination more through the years than reading young people with disabilities who are a year or two older than my children. I hope these young people help you and your family see into the future. They lead the way in a very new and exciting world.

PMR

Young Adults Speak Out:
Living the Course

Three young adults held a candid conversation led by Dr. Blum. Wendy Harbour, President of the Disabled Student Cultural Center at the University of Minnesota, began losing her hearing as a child. Today she is a young deaf woman, redefining her place in both the deaf and hearing worlds. Dave S. Johnson is a personal care attendant majoring in recreational therapy at the University of Minnesota. After acquiring a spinal cord injury at age 19, he began his life as a person with a disability. Chad Pierro is a transition health specialist at the PACER Center in Minneapolis, MN. He sustained a stroke shortly after birth and has lived with cerebral palsy since he was born. Here are some of their thoughts on moving into young adulthood.

On acquiring disabilities and being born with disabilities...

Dave: The biggest thing has been support—family support, mainly. When I became disabled, most of the friends I had no longer talked with me. They no longer wanted to do things with me, either because they were uncomfortable with me or didn't know what to do with me. I don't know which. I don't think I had a huge personality change! ... I do have two friends now who I had before ... they are pretty cool friends!

Chad: Unlike David, my condition—disability—came when I was born. I haven't known anything different. For me, it's like I didn't lose anything, so I really admire what Dave's done. ...

... I had to make a choice early on about who I would make associations with, and when I was younger I saw the community with disabilities as something I really didn't want to be a part of. I didn't like the stereotypes.... But in doing that, I lost part of my identity because I am a person with a disability and a person as well.

Wendy: I guess I started losing friends, because they didn't know what to do with me anymore. I didn't want to go to

movies. I didn't want to go to dances. I didn't like parties that were loud. And so for my own mental health, my own well-being, I lost friends. It wasn't them who severed the connection, it was me.

On the impact of having a disability on social relationships:

Chad: I think I see a lot of people being defined as "non-sexual" because they have a disability. It is something I had to find out on my own.

David: It took a while until I would ask a girl out again. I was self-conscious more than anything else. Even if she were very short, I would still look up to her. I think I stand 4'8" in my wheel chair, and going from 6'1"—that's really a difference.

Wendy: I went to private schools so I was pretty serious. I really didn't know anything about sex from anyone....
I researched sex on my own. I remember the only person who ever said anything about being deaf and my sexual life was the person who fitted my hearing aids. She said I'd have to learn to be an aggressive flirt, because if someone started whispering sweet nothings in my ear, I wouldn't hear them!

Chad: People do not properly acknowledge the full sexuality because it does not mean just intercourse. It does not mean getting what you want and just leaving. It means touching. It means feeling. It means hugging somebody. It means talking with somebody. It means intimate interactions. I didn't know that when I was younger and growing up. If I had more people when I was younger to tell me what I'm saying now, it would have helped me along.

Wendy: I have a different situation because I'm gay. Professionals will ask me if I'm sexually active and I say, "yes, sort of ... I need your definition"... because they are assuming all disabled people are straight. I think that the thing for me was getting involved in the DSCC [Disabled Student Cultural Center] and I got to know other gay disabled people.

Options

by Deb LaMarre

Students with disabilities in Independent District #287 come from 13 different towns. Some attend Edina High School and are part of the Bullets Program.

The progress made by these students has been remarkable. Student aide, Sage Summers, has helped these students since she was in 7th grade. Now as a junior, she says, "We are really proud of all our students. I really enjoy the rich rewards." Four attendants help the 10 students. The attendants are responsible for the student's progress, safety, and that of others around them.

Each student's daily program is adapted to his or her need. In addition, whenever possible, the students have "on-the-job-training" at restaurants like Fuddruckers, Pizza Hut or the Vo-Tech. The benefits of this are obvious. After all, isn't the main purpose of education to yield individuals who can contribute to society?

The Bullets are an interscholastic athletic team. The south suburban Bullets compete against neighboring teams of athletes in floor hockey, softball and soccer.

Some people debate the full inclusion of kids with disabilities in public schools. Some feel that with District 287 being funded by public school taxes, students with higher potential are being deprived. They feel class sizes could be improved. When addressing the issue of mainstreaming, one might ask, "What is the true purpose of education?" Is it not to produce an organized cooperative society? If so, everyone must be taught to tolerate diversity. They must understand that outside the borders of their school is a world full of people unlike them. They should not fear these differences, but embrace and learn from them.

Society has responsibilities to all its citizens. All Americans have the right to a life of fulfillment and accomplished goals. The Edina program and others like it meet these needs, and are beneficial to those enrolled and to the community.

Debbie LaMarre is a student in the ABC (A Better Chance) program at Edina high school.

Developing A Service Provision Report Card

Based on the comments made by Colleen Wieck, here's a "report card" you can use in evaluating the service you and your family receive from physicians, social workers, therapists, teachers, nurses—anyone who is helping to "Smoothing the Course of Transition for Adolescents with Chronic Illness and Disabilities." The left side represents the most positive qualities and the right side represents the least positive qualities.

	A	B	C	D	E	
Helps me feel hopeful						Makes me feel hopeless
Helps me believe in myself						Makes me feel doubtful
Helps me identify my strengths						Only wants to identify my deficits
Expects a lot from me						Expects very little from me
Believes everyone has the same goals, just different access and resources						Believes people with disabilities have different goals
Appreciates that people have different kinds of knowledge						Believes that professionals know better
Relies on the common wealth of communities						Relies on the "experts"
Believes minority cultures are valuable						Believes minority cultures are inferior
Accepts consumer norms and goals						Accepts bureaucratic norms and goals
Lets consumers choose for themselves						Makes decisions for consumers
Shares power among the people						Uses power over people
Views difference as an asset						Views differences as inadequacies

Charting the Course
from page 53

when "it" is going to happen. Parents must constantly reevaluate: "Should my child drive? At what point should he or she reduce medication?"

Blum explains that the role of an adult, parent or other caring person is very powerful.

In a 35-year longitudinal study of children growing up on the island of Kauai, Hawaii, researcher Emmy Werner learned that 50% of the children who originally told her they had a disability at age 10 reported that they did not have a disability when asked the same question 10 years later, at age 20.

"Disability and chronic illness don't just vanish!" Blum explained. What Werner discovered seems even more puzzling: The conditions that "vanished," crossed a whole range of diagnoses. Those who said they didn't have a disability, said whatever "it" was, didn't limit their lives. They often recalled a parent or other adult who stayed with them and nurtured their conviction.

"We know that having high expectations makes a difference," Blum says. "For those in Werner's study who grew up believing in themselves, they went on to function at a very different level than those who saw their lives as handicapped."

528

TM2000 SERIES by MARKELL

Markell is committed to the best in therapeutic foot products. With an eye to the future we have created a true orthopedic sneaker for children.

The TM200 Series has the following features:

- Symetrical straight last.
- Added depth – 3/16" (5mm) deeper than our conventional straight last shoes, to accommodate orthotics, AFO's and internal modifications.
- Extended counters firm enough to provide support and stability.
- Whole and half sizes from Infants' 6 to Youths' 2.
- Widths – a choice of Medium to Wide.
- Removable cushioned insoles.

Available through shoe stores and orthotics & prosthetics facilities worldwide.

© M.J.Markell Shoe Co., Inc.
504 Saw Mill River Rd., Yonkers, NY 10702, USA
or P.O.Box 246, Yonkers, NY 10702, USA

Circle # 51

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution

- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

Order Now by Calling
1-800-847-8887

Available in Black or Beige

TEMASEK
TELEPHONE INC.
21 Airport Blvd. #G., So. San Francisco, CA 94080

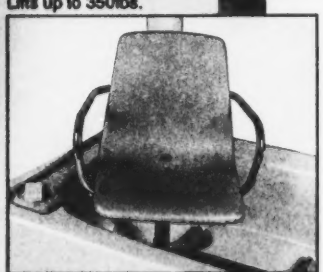
Circle # 202

BATH-MATE ™

Water Powered Bath Lift

The Bath-Mate fits your existing tub without modifications

Water pressure alone supplies the lifting action. Lifts up to 350lbs.



Safe Bathing Promotes more Independence....

The Bath-Mate raises slowly to wheelchair height and lowers within 2 inches of tub bottom.

The bath chair pivots outward for safe transfers.

Optional:
- Seat Belts
- Arm Rest

(800)947-6565

P.O. Box 80095 Ontario, Ca. 91758

Circle # 67

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

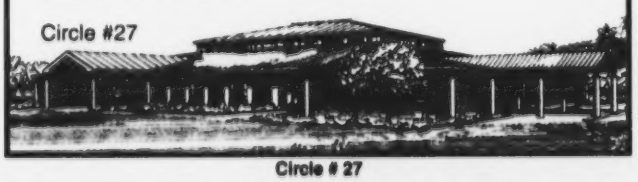
Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27



Circle # 27

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

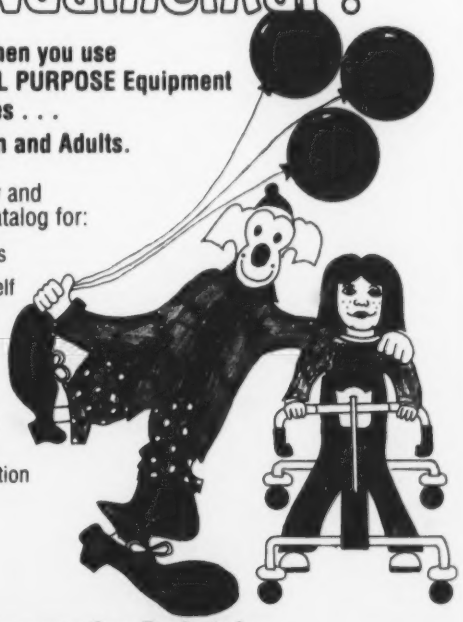
Circle # 26

Is Your Therapy FUNdamental™?

It can be when you use our SPECIAL PURPOSE Equipment and Supplies . . .
For Children and Adults.

See our New and Expanded Catalog for:

- Mobility Aids
- Do-it-Yourself Supplies
- Positioning Furniture
- Wheelchair Accessories
- Learning & Communication Aids



Since 1978

Consumer Care Products Inc.
810 N. Water St., P.O. Box 684
Sheboygan, WI 53082-0684
Tel: 414-459-8353
FAX: 414-459-9070

Circle # 109

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
	Abilities Expo	37
9	Accessable Environments	40
3	Adaptive Design Shop	14
	Apple Computer	19
128	Aquatec Health	18
216	Assoc. for Special Kids	48
218	Assoc. of Birth Defect Children	49
219	Attainment Company	18
167	Ballard Medical Products	30
217	Barrier Free Lifts	45
6	Berkshire Meadows	14
7	BHC-JA Preston	C4
8	Bruno	63
10	Charles C Thomas	23
186	Civitan International	18
227	Clinician's View	7
13	Columbia Medical	28
12	Columbia Medical	32
11	Columbia Medical	38
109	Consumer Care	58
16	Convaid	17
17	Crotched Mountain Rehab	41
14	Crow River	27
18	Cumberland Hospital	43
19	Devereux	67
20	Duraline Medical Products	64
152	Electric Mobility	11
25	Equipment Shop	51
26	Estate Planning	58
27	Evergreen Center	57
29	Flaghouse	62
30	Ford	C2
	GM	13
35	Handi-Move	29
36	Haverich Ortho-Sport, Inc.	67
38	Heartspring	6
39	HMS School	62
40	Homecare	39
121	IBM (Special Needs Systems)	32
42	Innovative Products	25
211	InvoTek	18
212	James Leckey Design	22
45	Kennedy Krieger	64
46	Kid-Kart	15
147	Kimberly Clark	5, Insert 34A–D
48	Laureate Learning	C3
169	Milani Foods	33
51	MJ Markell Shoe Co	57
171	New England Center for Autism	62
219	Oralgiene	3
161	Pathfinder Village	47
214	Richer Life	51
66	Rifton	47
67	Rollins Healthcare	57
68	Sentient Systems	51
71	Special Design	40
189	Sportime	22
75	St. John's Villa	52
77	Stewart Home School	29
78	Stroller Pak	29
120	Teledyne Brown	26
202	Temasek Telephone	57
82	Triaid	47
215	Tomorrow's Child	64
188	Whitmyer Biomechanix	29
162	Willow River Farms	52
86	Woodbury Products	51

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000
2❑ $30,001 - $40,000 5❑ $75,001 - $100,000
3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date: July 31, 1994

Expiration Date: October 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000
2❑ $30,001 - $40,000 5❑ $75,001 - $100,000
3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date: July 31, 1994

Expiration Date: October 31, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

532

Bibs

Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No online charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Clothing

Richman Cotton Company
100% Cotton Clothing & Blankets
Easy to dress. Easy to see.
FREE Catalog. 800-992-8924.

Special Clothes
PO Box 4220
Alexandria,VA 22303
(703) 683-7343

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical
Savings to 25% on Tumbleforms. Equipment and Supplies Discounted to 50%. Call 800-877-9100. Free brochure.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Rehabco
1513 Olmstead Ave.
Bronx, NY 10462
(718) 829-3800
45 years as New York's oldest and best Rehab. dealer. Experts in children's mobility & custom seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Please call or write us today for more information and quality service.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Books, Audio/Video & Educational Material

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Publications

Hydrocephalus News/Notes
Published quarterly for affected individuals/ families & professionals who specialize in their care. Highlights: medical/technical articles, human interest stories, great resources! A. Liakos, Editor, HNN, 1670 Green Oak Circle, Lawrenceville, GA 30243. $25 year.

BEAT THE HEAT!
- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927
Made in USA Pat. 5168889 *Providing Comfort to Those Who Want It!*

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Florida

Home Medical Equipment Co.
2137 Fowler St.
Ft. Myers, FL 33901
(800) 226-0404
New/Used Vans and equipment for the physically challenged. Full service and repair center. NMEDA member. Nationwide delivery.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE

Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- *Aquatic Aids/Sports* Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE

150 No. MacQuesten Pkwy., Suite 95885, Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

Circle # 29

We Can Make A Difference!

"Now I can see my beautiful daughter flourishing and making progress that I never thought possible! Thank goodness for a place like this school."

-Parent
Intensive Program

When you feel that there isn't any answer, when you feel there are no other options available, **DON'T GIVE UP!** Our Intensive Program makes a difference for students with serious, challenging behaviors. We accept students who require the specialized care that other schools just cannot provide. We give our students state-of-the-art educational and residential programs free of painful aversives and excessive medication.

Many of our students arrive at the New England Center for Autism after having had a long history of rejection and failure. With us they receive intensive, positive, behaviorally oriented treatment that focuses on developing the coping skills and appropriate behaviors which enable them to live and work successfully with minimum support. Intensive Program students participate in the full range of academic, community, and recreational activities provided for all of our students.

*Let **The New England Center for Autism** make a positive difference in your child's life.*

For more information on our Intensive Program, please contact **Catherine M. Welch, MEd, Director of Admissions.**

The New England Center For Autism

The New England Center for Autism
33 Turnpike Road, Southboro, MA 01772
(508) 481-1015
Just 20 miles from Boston

Circle # 171

534

WHAT'S HAPPENING

SUPPORT GROUPS

• The Dystonia Medical Research Foundation is making a special effort to reach out to young people with ***dystonia***, a disorder dominated by involuntary muscle contractions that interfere with movement and posture. They have published a free booklet, *"8 to 18" A Guidebook for Young People with Dystonia*, which addresses medical treatments, educational rights, social-emotional concerns and "tricks" for coping. The Foundation also provides a *Young Person's Newsletter* and Pen Pal Network; plans for a computer network for young people are in the works. Contact the Dystonia Medical Research Foundation, One East Wacker Drive, Suite 2900, Chicago, IL 60601-2001, (312) 755-0198.

• The Association for Hydrocephalus Education, Advocacy, and Discussion (AHEAD) is a national network of people with ***hydrocephalus*** and their families. The purpose of the group is to provide support; the organization does not provide medical referrals or information. Members are able to contact each other through telephone conversations, letters and the Prodigy online service. Regional chapters exist throughout the United States and there is a special subgroup for parents of young children with hydrocephalus. Membership is free; applications are available from Shawn Crudup, 2106 Concord Dr. Apt. A, Chesapeake, VA 23324, (804) 543-3275.

• The mother of a child with ***DiGeorge syndrome*** has started a national support network for parents of children with the syndrome. The group offers information and resources pertaining to DiGeorge syndrome, and helps parents in the same area of the country contact each other. For more information, contact Natalie Ward, 27859 Lassen St., Castaic, CA 91384, (805) 294-3623.

PUBLICATIONS

• Let's Face It, a support network for people with facial difference, publishes an annual directory, *Resources for People with Facial Difference*. The 40-page booklet lists relevant organizations, books and videos, and has special sections listing resources especially for parents, children and young adults. This publication normally costs $10 but is available free to *Exceptional Parent* readers who request it and include a 9 × 12 inch, self-addressed envelope stamped with postage in the amount of $2.90. Let's Face It, Box 711, Concord, MA 01742-0711, (508) 371-3186.

• *ADD-ONS* is a bimonthly newsletter described by publisher Mary Daum, the mother of a nine-year-old child who has attention deficit disorder (ADD), as a "paper support group" for people living with ADD. All aspects of ADD are discussed and reader participation is encouraged. The newsletter is available from *ADD-ONS*, P.O. Box 675, Frankfort, IL 60423; $15/year.

LIFE
CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL®
THREE-OR-FOUR WHEEL, RWD SCOOTER
Choose the ride that's fit for you. Regal is available in seven models, all ergonomically designed to give your journeys freedom of choice and comfort.

BACK-SAVER™
REAR EXTERIOR WHEELCHAIR LIFT
Easy to use. No lifting. Fully automatic. Raises and stores manual wheelchairs with the turn of a key activated switch. Only 1 of 14 different Bruno Lifts.

CURB-SIDER™
SCOOTER & WHEELCHAIR LIFT
Unique 180-degree power rotation lets you pick up next to or behind your vehicle. Ideal for use in vans and trucks with liftgate or tailgate rear openings.

ELECTRA-RIDE™
STAIRWAY ELEVATOR SYSTEM
Low-cost, battery-powered stairway elevator. Needs no special wiring. Operates even if there is a power outage. To give your journeys peace of mind.

BRUNO®
INDEPENDENT LIVING AIDS

© BRUNO INDEPENDENT LIVING AIDS, INC. 1993

CALL 1-800-882-8183 TOLL FREE OR 1-414-567-4990 FAX 1-414-567-4341
BRUNO INDEPENDENT LIVING AIDS, INC. 1780 EXECUTIVE DRIVE PO BOX 84 OCONOMOWOC WISCONSIN 53066

Circle # 8

Children's laughter is music to our ears.

Our dedicated staff at the Kennedy Krieger Institute is devoted to helping children and adolescents with physical, mental or educational disabilities. Through diagnosis, treatment and education, we can help find the key that unlocks the future for your child and your family.

Kennedy Krieger Institute...providing quality services for youngsters of any age with:

- Assistive Technology Needs
- Motor and Language Delays
- Metabolic & Degenerative Diseases
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

Kennedy Krieger Institute

A comprehensive resource for children with disabilities

Call us to talk about your concerns, slight or severe. We can help.

(410) 550-9400 / 1-800-873-3377
707 North Broadway
Baltimore, MD 21205

Circle # 45

123 123 123 123 123

A B C

Where kids can be kids!

Prescribed daycare facility
for medically complex children
Ages 3 months - 7 years

- Skilled Nursing Care
- Therapy Services
- Educational Development
- Infusion Therapy
- Interaction with other children in a developmentally stimulating environment

Tomorrow's Child
CENTERS FOR MEDICALLY DEPENDENT CHILDREN

Centers nationally located. For information call
(609) 354-9106

123 123 123 123 123

Circle # 215

Don't You Have Enough To Worry About...

Without Worrying About Incontinent Supplies?

DMP®
DURALINE®
MEDICAL PRODUCTS

- For all of your bladder and bowel control needs - diapers, briefs, liners, underpads, catheters and more.
- Fast direct-to-your-door delivery.

Call Today For A FREE Catalog!

1-800-654-3376

DURALINE MEDICAL PRODUCTS
324 Werner St. • P.O. Box 67 • Leipsic, OH 45856

Circle # 20

536

NEW PRODUCTS

THERAFIN SCOOTERBOARDS

These boards are designed primarily for use with children to encourage extension, provide vestibular stimulation and promote head and upper trunk control. They are available in single and twin carpeted models and a single uncarpeted model. All models have four large casters.

Therafin Corporation, Mokena, IL 60448-0848

Circle # 221

BIG/LITTLE II

This pre-reading tutorial and modified game program teaches children the concepts of big and little, categorizing and classification. The single-switch scanning program allows up to four players to construct a bear in various sizes by selecting appropriate body parts and clothing. For Apple II and Macintosh computers.

UCLA/LAUSD Microcomputer Project, Los Angeles, CA 90024

Circle # 222

ACTION ROCKET

One chair for various ages! This rigid-frame, manual wheelchair will grow with a child—from a tiny 10 × 10 inch frame to a teen-sized 16 × 16 inch frame. Quick-release wheels and arms and a fold-down back make this chair easy to transport to all the places children need to go; the expandable width and depth fits them as they grow! Many accessories and options are available.

Action by Invacare, Elyria, OH 44035

Circle # 223

EARLY RECOGNITION INTERVENTION NETWORK (ERIN)

ERIN is a compilation of academic tutorial and assessment programs designed as a curriculum for students with early childhood learning disabilities. Assessment tools, curriculum guides and hands-on activities are included on two disks—one for infants and toddlers, the other for primary school-age children. For use on Apple II or IBM-compatible computers.

J. E. Stewart, Seattle, WA 98155

Circle # 224

THE APPLAUSE

This lightweight manual wheelchair fits young adults and is easy to fold and transport. Its construction of aerospace-quality aluminum and graded hardware provides strength and durability with a weight of only 30 pounds (without footrests). Removable swing-away footrests, padded rear-pivot armrests and a lifetime warranty on the sideframe and crossbrace are just of few of its many features.

Damaco/Freedom on Wheels, Chatsworth, CA 91311

Circle # 225

THE PRO-CYCLE

Now available for both youths and adults, this three-wheeled handcycle lets teens with mobility disabilities take over the bike path! Each cycle is custom built to the user's height and will accommodate individuals with heights of four feet to more than six feet. Shimano components, quick-release hubs, a chain guard, adjustable crank shaft to fit individual arm length and an internal drum-reversing brake system are all standard! Custom paint jobs, quad cuffs, racing or mountain bike tires and a cordless computer are just a few of the options that can make this cycle the envy of the neighborhood.

Top End by Action, Pinellas Park, FL 34665

Circle # 226

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

FAMILIAR FACES

*Three-year-old **Jonathan Feres** enjoys a day at the beach. Jonathan, who lives in Quebec, Canada, has Down syndrome and a severe hearing loss. Jonathan attends an integrated preschool program that was founded by his adoptive mother, Pamela, and other parents. Jonathan, who was born in Cambodia, may soon be joined by an adopted Cambodian sister.*

*Sixteen-year-old **Christine Adrian** gives a lift to rollerblading cousins Bobby and Mallory. The three are navigating a hill near Christine's home in Romney, West Virginia. Watching the action from the sidelines, Christine's dad, Herb, and aunt, Sharon, seem to be having as much fun as the kids. Christine's mom, Sandy, says that looking at this picture always makes her smile! Christine has cerebral palsy.*

***Brianne Nicole Prada** of Turlock, California is described by her mother, Karen, as "a very determined little girl." Brianne, 32 months, has Cornelia de Lange syndrome (CdLS). She was born with only one finger at the end of each arm, but, Karen says, "that doesn't seem to slow her down." Brianne's picture also appears in a brochure that is available from the CdLS Foundation (1-800-223-8355).*

*Pre-teens (from left to right) **Amber Lund**, 11, **Lacey Mosteller**, 10, and **Ana Gimlen**, 10, show off their "shiny" smiles at Disneyland. All three girls were born with cloacal exstrophy, a condition that has required one or more ostomies and constant monitoring of kidney function. Lacey's mom, Lee, says that despite the hundreds of miles between these special friends, they try to get together as often as possible.*

*Three-year-old **Heather Wiegman** giggles while posing with her mother, Carolyn. Born nine weeks prematurely, Heather, who lives in Orlando, Florida, has cerebral palsy. Carolyn, who wants to "stress the importance of advocating for children with disabilities," has many goals for Heather's future including a motorized wheelchair, enrollment in a private Catholic school and a canine companion.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

538

Health Insurance Troubleshooter

continued from page 16

to speak with a variety of people involved in health insurance issues—consumers, insurance company executives and attorneys, industry spokespeople, Medicare experts, government representatives and legislative officials.

Over the years, I've learned a lot about the way insurance companies work and about the types of health insurance claim problems that occur. I've learned that such problems are often complex and involve a variety of technical issues. Unless consumers have a background in health insurance, economics or law, they generally find it difficult to fully understand the issues involved.

Many parents of children with disabilities are quite knowledgeable about insurance issues. By necessity, they have become sophisticated in regard to this and other issues of concern for their children. Still, few have technical backgrounds. *Health Insurance Troubleshooter* will be written in a clear, easy-to-understand style, with appropriate examples to illustrate specific issues.

If you're having a problem obtaining health insurance for your child, if you have health insurance but are having difficulty obtaining appropriate insurance benefits or if you have a general question about health insurance, write and let me know. If the problem relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number so that I can get in touch with you if further information is necessary. To insure privacy, only your initials and state will be used in the column. Due to time limitations, it is not possible to respond to letters individually, but I will choose as many letters as possible to discuss in this space.

Write to me at *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. I look forward to hearing from you.

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich

ORTHOPÆDIC CYCLES

Europe's leading line of specialized cycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

Circle # 36

At Devereux . . .
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

CHILDREN'S PAGE

OH BROTHER!

by Katie Hershberger

My 10-year-old brother, Jeff, has autism. Many people with autism also have mental retardation, but Jeff does not. Jeff has always been good with numbers. He learned to multiply in first grade. He can also spell well. Sometimes some of the kids in his class might ask him how to spell a word.

Jeff likes fans because they spin around. He enjoys just sitting in front of a fan and watching it spin. He always remembers all the fans that he sees. If he visits someone's house, he will memorize the location of all the fans. The next time he goes to that house he might ask, "Where's the fan with the three blades and the broken knob?"

Jeff has to have a routine. If we change just one little thing he gets mad; that makes me mad. If we are going somewhere, he has to know where we're going and what time we are supposed to leave. If we are even one minute late, he'll say, "We were supposed to leave at 4:00! Now it's 4:01!" But he doesn't really understand time. To him, time is just numbers.

One time, I was drawing and Jeff tried to draw the same thing. I got mad at him and told him not to copy me. Then my parents told me that that's how he learns—by imitation and repetition. For example, if he rents a video and there's one part he likes, he will just keep rewinding it and watching it over and over. I get tired of hearing it all the time.

When my brother began attending public school, he became popular with his classmates. I think the kids were interested in him because first of all, he's a lot bigger than they are—some people say that he looks like a football player—and because they'd never seen anyone with autism. They would talk to him and ask him questions. That soon became too much for him. He can't take too much stimulation at once.

Once we were in a restaurant and a family with a baby came in. Jeff said, "Oh no! Here comes a stupid baby!" Jeff said that because he literally can't stand the sound of babies crying. If he hears one, he will plug his ears and make a humming sound so he can't hear it.

Jeff does not socialize well. If someone he knows comes up to talk to him, Jeff might say, "Go away." It doesn't mean that he doesn't like them—just that he doesn't want to talk.

Living with a brother who has autism has had its ups and downs, but all in all, I'd say it has been a good experience.

Katie Hershberger lives in Goshen, Indiana. She wrote this essay about her brother when she was 12 years old. She is now 15 and will be a sophomore at Goshen High School where she plays the clarinet in the marching band. She also takes piano lessons and enjoys art, writing and playing Nintendo games with her brother, Jeff.

Jeff is 13 years old and will enter seventh grade at Goshen Middle School. He has been successfully mainstreamed since second grade. He has a playing card collection, an electric fan collection and many stuffed animals. His big dream is to turn 16 years old and drive a Ford Mustang.

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to:

Children's Page
Exceptional Parent
209 Harvard Street,
Suite 303
Brookline,
MA 02146-5005

Spectacular Summer Software Sale

50% OFF all Laureate software

From Words & Concepts

For over ten years, Laureate has been producing programs to meet the unique needs of exceptional children. We want your child to benefit from using our award-winning software at home. That's why we're reaching out to parents with this *Spectacular Summer Software Sale.*

From now until August 31, 1994, you can purchase Laureate's talking software programs for an incredible 50% off. We'll even pick up the shipping charges! Your satisfaction is guaranteed. If our software doesn't meet your child's needs, for whatever reason, we'll take it back.

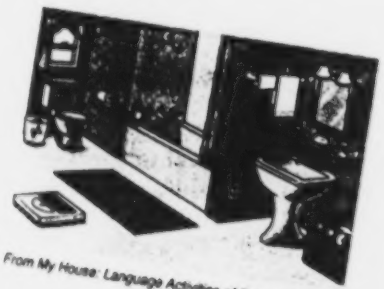
Available for Apple II, Apple IIGS, IBM, and Macintosh computers

Call today for a free catalog.

1-800-562-6801

This offer applies to individuals only. No school, agency, or institutional purchase orders, please. We will accept orders prepaid by check, MasterCard, or VISA. Free shipping within the U.S. only. Please mention this sale when placing your order.

From Exploring First Verbs



From My House: Language Activities of Daily Living

We have over 60 talking software programs for children functioning between 6 months and 8 years of age.

- **Language intervention**
- **Cognitive processing**
- **Reading**
- **Instructional games**

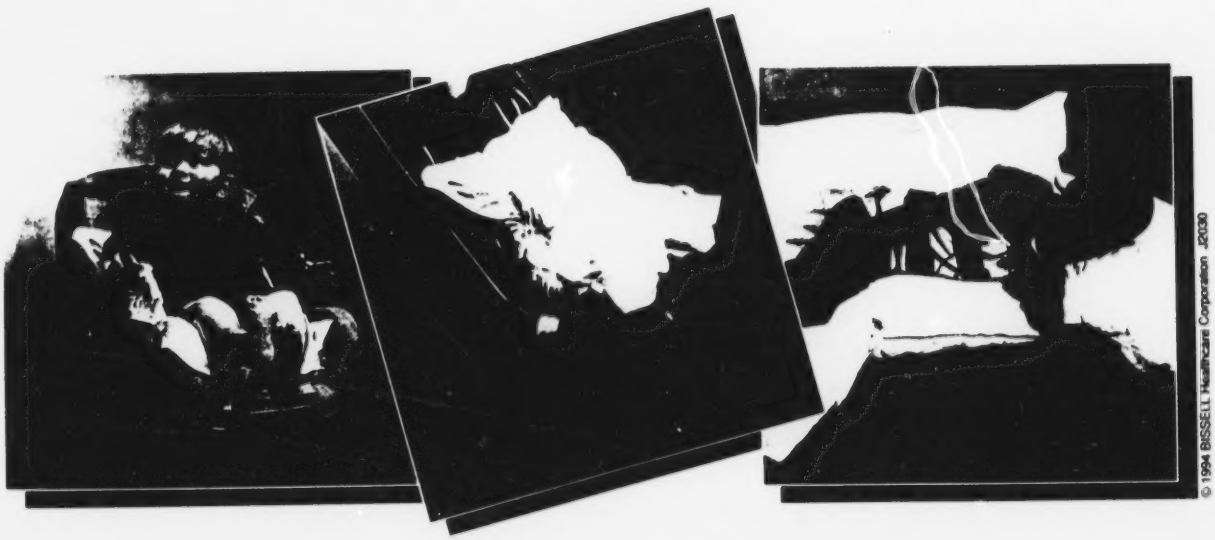
Laureate

541

Circle # 48

Laureate • 110 East Spring Street • Winooski, VT 05404 • 802-655-4755

The Shape of Things to Come...



© 1994 BISSELL Healthcare Corporation J2030

Did you ever think you'd see one affordable product that meets a wide variety of positioning needs? Introducing Versa Form—the latest in positioning technology from Tumble Forms.

Simple, yet effective, Versa Form consists of a vinyl pillow filled with styrene beads. When vacuum pressure is applied, the result is a precisely molded, but modifiable positioning device. It will quickly mold to any client, providing firm, comfortable support. Best of all, Versa Form can be reused as often as you'd like by simply releasing the vacuum and reshaping the vinyl pillow. Tests show Versa Form can easily withstand repeated use.

Now you can provide specialized positioning for clients requiring additional support in sitting, sidelying, prone or supine positions. Versa Form can also provide specific extremity or joint stabilization. All this with one product...Versa Form from Tumble Forms.

For more information, call 1-800-631-7277. In Canada call 1-800-665-9200.

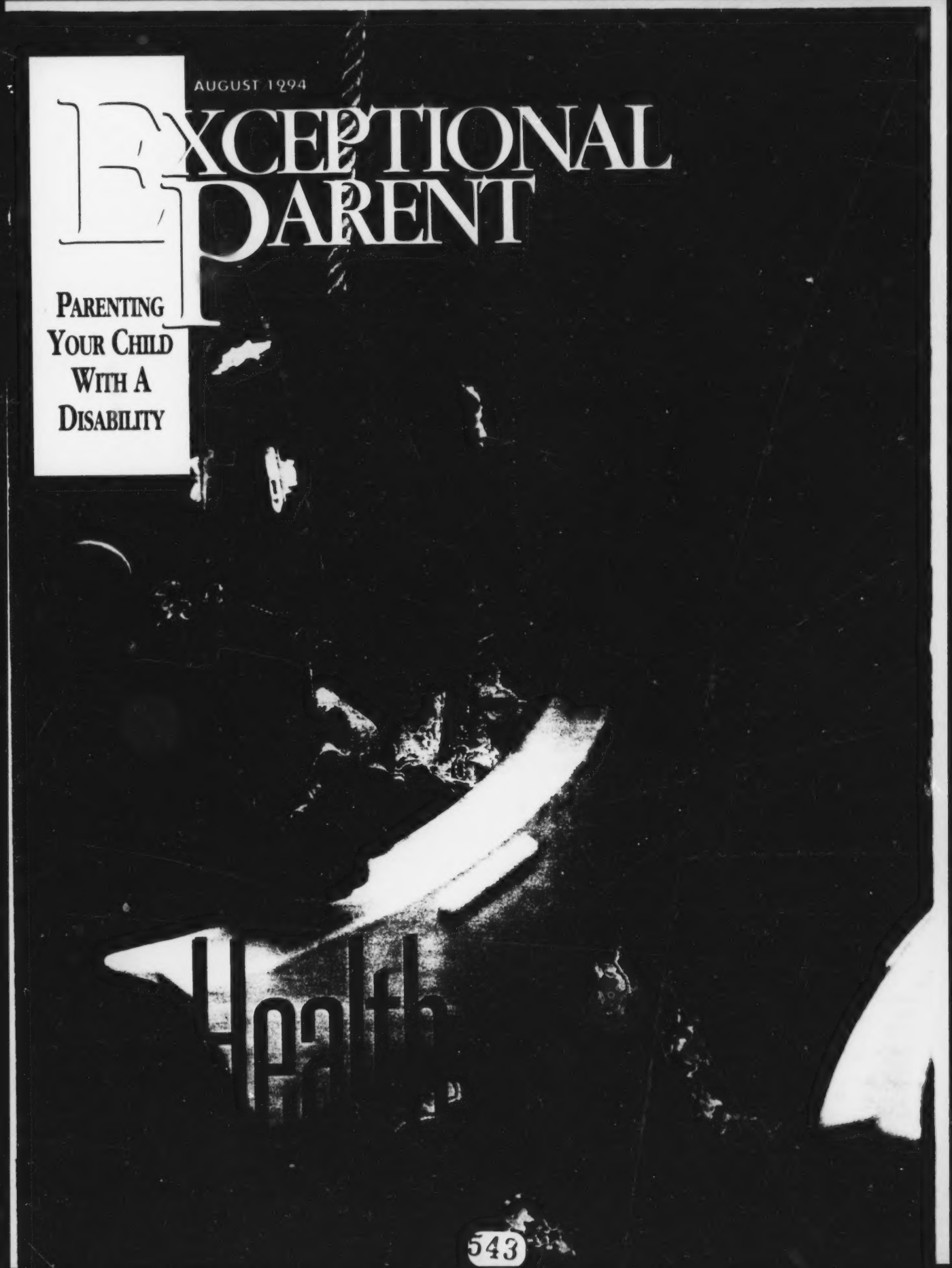
VERSA FORM™ by Tumble Forms

Circle # 7542

AUGUST 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

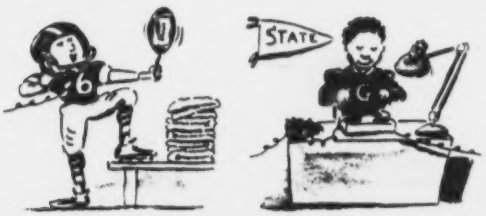


Health

How easy is it to call at anytime with AT&T Long Distance Relay Service?

This easy: 1 800 855-2880 (TTY)

Anyone. Anywhere. Anytime.



No matter when you call, state-to-state and international long distance relay calling is easier than ever with one easy number from AT&T. And relay savings are easy too. With AT&T **True USA**℠ Savings, you can save when you spend as little as $10 a month on AT&T Long Distance calls.* At AT&T, we're dedicated to making phone calls easy for anyone. Anytime. Anywhere.

1 800 855-2881 (Voice) · 1 800 855-2882 (ASCII) · 1 800 855-2883 (Telebraille)

*For more information or enrollment, call 1 800 833-3232 (TTY).

AT&T

Proud Sponsor of the World Games for the Deaf

54 i

Circle # 2

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

AUGUST 1994
VOL. 24, ISSUE 8

COVER:
Two-year-old Reanna Dixson enjoys outdoor play with her mother, Gwen, during a Mommy & Me class at the Blind Children's Center in Los Angeles. Gwen, who has cerebral palsy and a visual impairment, is one of the young "stars" of LET'S EAT, *the Center's new video. For more information, see page 63.*

PAGE 38

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE**: Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

FEATURES

Mimi, My Friend by Anita Stohs 23
A mother talks about the special relationship between Mimi and her brothers.

The Parent and Professional Alliance Program 26
South Carolina parents become part of the medical education curriculum.

A Bit of Teenage Savvy by Peggy Mann Rinehart 30
Adolescents with disabilities advise health care providers.

Dental Care for Children with Disabilities by Steven P. Perlman 38
Dental disease can be prevented with daily oral care.

Special Bathrooms by Linda Nitteberg 45
Adaptations can make the bathroom a more user-friendly environment.

Manufacturers of Bathroom Access Aids 47

Manufacturers of Incontinence Products 50

DEPARTMENTS

Editor's Desk 2

Letters 4

Search & Respond 8

Ask the Doctor 18
Dr. David Hirsch talks about nutrition and growth.

Familiar Faces 21

Role Models: JOHN KEMP 34

Fathers' Voices: FATHERS ARE CAREGIVERS TOO! by Steve Fischer 43

Informational Forum: Networking 55

Health Insurance Troubleshooter 57
Insurance coverage for incontinence products.

Directory of Advertisers 58

What's Happening 63

New Products 64

Exceptional Parent Library 66

Children's Page: LIVING WITH MOEBIUS SYNDROME by Natalie Abbott 68

PAGE 26

EDITOR'S DESK

For most of our growing family of readers, concerns about adequate and compassionate health care are part of everyday life. This summer, it appears possible that some major health care reform legislation will actually work its way through the legislative process. Simultaneously, election campaigns for the House and Senate are gaining momentum. As a result, during the late summer and early fall, many of our elected leaders will be campaigning at home and working on health care legislation in Washington. Campaigns provide unique opportunities to tell our stories personally to our elected officials and those who aspire to replace them. Many readers have already found the time and energy to communicate with members of congress. They have told their stories to ensure that individuals with disabilities and special health care needs will finally have access to the kind of health care everyone deserves—and that caring parents will no longer have to beg, borrow or go bankrupt in their pursuit of that care. Now, during the campaign season, we must continue to deliver our messages.

STANLEY D. KLEIN, PH.D.

Research shows that parents' readiness to collaborate with health care providers is determined by the ways in which those parents and providers interact. When parents are respected as the most important experts in the care of their children and when providers are compassionate and understanding, children and parents do better—and at no extra cost! When I heard a presentation by parents in South Carolina involved in a wonderful program called the Parent and Professional Alliance (PAPA), I invited them to share their story with our readers. PAPA is a group that is having a profound impact on the education and training of physicians and other health care providers. While we are pleased to bring you their story in this issue, we know there are other, similar efforts underway in other parts of the country. We are working on identifying these other programs—to do so, we need to hear from involved parents.

As Peggy Mann Rinehart explains in *A Bit of Teenage Savvy*, young people with disabilities and/or special health care needs can also influence the training of health care professionals. This is especially true when the professionals realize that health care consumers—children as well as parents—have a great deal to teach.

For many parents, access to adequate, compassionate dental care is one of their most difficult health care challenges. Steven P. Perlman, D.D.S., a member of *Exceptional Parent's* Editorial Advisory Board, and other members of the Academy of Dentistry for People with Disabilities are devoted to changing that reality. They are working on the creation of educational materials on oral health for parents and children; they are also working to change the educational preparation of dentists and oral hygienists—goals not unlike those of the PAPA parents. In this issue, Dr. Perlman presents the first of a series of articles with practical information on dental care for children with disabilities.

Bathrooms are daily centers of activity that can require special attention and equipment so that children can gradually learn to care for themselves as independently as possible. In *Special Bathrooms*, Linda Nitteberg provides bathroom safety and design suggestions; her article is accompanied by a directory of manufacturers. This issue also includes a similar directory of manufacturers of incontinence products along with a discussion of health insurance reimbursement for incontinence products. (See "Health Insurance Troubleshooter.")

At every Abilities Expo I have attended this year, I have had the pleasure of meeting informally with readers to listen to their suggestions and concerns. The topic of relationships between sisters and brothers have come up in each of these meetings. In *Mimi, My Friend*, Anita Stohs shares her observations and insights about the special relationships among her three children. In the September issue, we will begin a series of excerpts from a very important new book about siblings.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology,
New England College of Optometry

ASSISTANT EDITOR Kim Schive

EDITORIAL STAFF Valerie Steele

EDITORIAL INTERNS
Jennifer Fisher Ludmilla Panza
Sara Wood Pyongson Yim

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Sutera

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferrante

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (CO, IN, KS, MN, ND, No OH, SD, UT, WI)
Anthony Arnone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, MI, MO, NB, So OH)
John Maisel
(708) 416-0780 Fax (708) 416-0793

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
William Hague
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESIDENCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

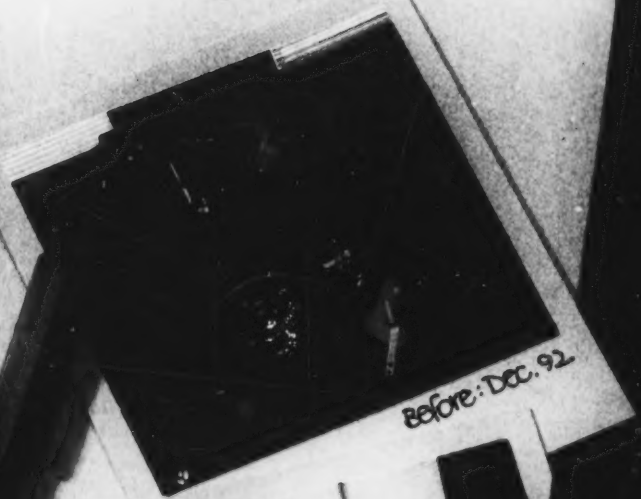
COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58. BPA International Consumer Magazine Membership Applied for August 1993.

546

GS: Progress Report



Outcomes: Posture, function, and mobility improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

LETTERS

Laughter Helps!

I agree with the letter from P.C. (May 1994) that humor is a real survival tool for the families of loved ones with disabilities. I can never resist telling the following story to coworkers who are feeling frustrated with toilet training their toddlers:

My youngest son, Adam, is nine years old and still not potty trained due to severe mental retardation and a real lack of motivation on his part! He also dislikes water—bathing and swimming are not his idea of fun activities.

After six years of trying to get him to use a potty chair, I got the bright idea of having him try to stand up and pee into the toilet—a skill his older brother had mastered by the age of two. It was right before bedtime and Adam was wearing only a diaper and tee-shirt. I stood him in front of the toilet, lifted the seat and reached for the faucet to turn on the water—the old running-water-makes-you-go trick. This was a mistake; as soon as I let go of his hand, Adam took a giant step forward—into the toilet. He was so proud of himself for stepping right into that water that he just grinned from ear to ear and looked at me as if to say, "How about that, Mom?"

What could I do but laugh? I lifted him out of the toilet and sat down on the floor and laughed so hard that the tears rolled down my face! I still get a big smile every time I remember the look on his face. He was one proud little boy! I just wish he'd get that excited on those rare occasions when he uses the potty. Oh well, that's life with Adam!

M.S., Pennsylvania

Indispensable Information

I have been meaning to write to *Exceptional Parent* for several years. The information this magazine provides and the stories families share are indispensable.

The membership of our organization—Mothers of Supertwins (MOST)—consists of families of triplets, quadruplets, quintuplets and sextuplets. Almost all of our babies are born prematurely and need some NICU stay. We strongly support high-risk clinic follow-up for *all* preemies and early intervention programs when needed. Just as in the general population, our member families often face a number of physical or developmental challenges with one or more of their children. I refer to your annual resource directory (January 1994) on a daily basis. The *Search* column has been a godsend to several of our families.

I'm thrilled that your publication is now being offered on a monthly basis. Keep up the wonderful work!

M.A.B., New York

EDITOR'S NOTE: MOST can be contacted at P.O. Box 951, Brentwood, NY 11717, (516) 434-6678.

Language Reveals Prejudices

I was rather surprised by the letter from S.R. of Washington (April 1994) who wrote, "As the parent of a child with Down syndrome who—*thank God* (emphasis added)—does not have physical limitations..." I thought that was a rather insensitive remark. How would this parent feel if I had written, "As the parent of a child with orthopedic disabilities who—thank God—is not developmentally delayed?"

As we strive to educate the general

EXCEPTIONAL PARENT

- *To reach out to parents of children with disabilities and special health care needs.*
- *To empower mothers and fathers by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

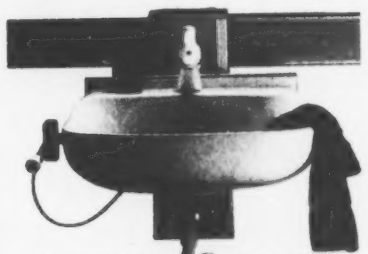
LISA BLUMBERG, J.D., Corporate Attorney, Aetna Life Insurance, West Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Franciscan Children's Hospital, Boston, MA
SANDRA B. FLEISHMAN, Parent, Coordinator, World of Difference Project, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Inc., Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, New City, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President & CEO, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

548

How do you take a sit-down shower? How does a sink go up and down? How do astronauts go to the bathroom?

Talk about your awkward situations. Astronauts first strap themselves in with foot and thigh restraints. They've got a toilet bowl but no water. Instead, 12 air jets underneath the seat propel everything into a storage tank.

Hot water might just be the best problem solver around. This comfortable, movable, contoured shower chair lets you soak it in without a care. Our Ceratherm shower with thermostatic control makes you feel even more at ease.



Our Multi-System Lavatory is the closest anyone's come to a portable sink. It adjusts very quickly to accommodate wheelchairs, those with back trouble, or anyone tall, short or in-between. It even slides to the left or to the right.

Everyone goes to the bathroom. In very different circumstances. Still, it should always feel inviting. Private. Relaxing. It should be a chance to feel free. To that end, American Standard offers the biggest choice of smartly designed, stunningly designed accessible products anywhere. We'll also answer all your questions. Even if we have to ask NASA. Just call us at 1-800-217-1929. *American Standard*

Circle # 234

©1994 American Standard, Inc.

public on their use of language as it relates to our children, we must also look inside ourselves. Many times, our choice of language reveals our inner stereotypic thinking and prejudices.

If we want the world to value our children—to stop segregating, stigmatizing and staring at them—we first need to clean up our own acts.

J.L., California

Remembering Daniel

I had to write after reading Nathan Reiff's *Children's Page* article, *Remembering Daniel* (June 1994).

My three-year-old son, Stephen, also has pyruvate dehydrogenase deficiency. He has a nine-year-old brother, Trevor, and an eight-year-old sister, Meghan.

I was so moved by Nathan's article because of the love that was given to Daniel. We love Stephen just as much and cherish every day we have with him.

Thank you for a wonderful magazine!

A.B., Pennsylvania

Thanks!

Thank you for your truly wonderful magazine. I don't know what I would do without it. I devour each issue the day it arrives because I am so hungry to find information about how the system works and about disabilities in general.

My son, Jeremy, is only two years old, so we're relatively new to the wild and wonderful, but also wacky world of disabilities. It's sometimes difficult to live here, but the people are caring, the pace is slower and we've grown to appreciate a whole new part of life.

P.G., Ohio

An Outpouring of Support

Thank you so much for publishing my *Search* letter (*Benign Congenital Hypotonia*, April 1994) and forwarding the responses. The outpouring of support has been wonderful.

S.C., Virginia

Missing F.Y.I.

I am writing in response to the changed format in your magazine. Overall, I enjoy the content matter very much and find it quite informative.

However, I do miss the brief column you used to run called *F.Y.I.* In each issue, this column highlighted a specific disability or condition. I found it particularly helpful when you highlighted uncommon or rare disabilities on which little information can be easily found.

Please consider resuming this column. It didn't take up much space, so you should be able to squeeze it in somewhere. Thank you.

D.V.W., Oregon

EDITOR'S NOTE: We have heard from several readers who miss the F.Y.I. column. We are planning to bring it back on a regular basis in the near future. Thank you for taking the time to write to us.

A Sense of Connection

I'm the parent of a five-year-old boy who has cerebral palsy. I would like to thank you for continuing to publish a magazine that provides my wife and me with a sense of connection and a feeling of support. We look forward to receiving your magazine each month.

We have started a parent support group in our area and *Exceptional Parent* magazine has been a big help to our group.

I think it would be good if you started a pen pal page and let us have the option of using our full names and addresses. This would allow parents of children with the same disabilities to find each other.

T.M., Texas

☐ Yes! Yes! A pen pal page, please. My son wrote to the boy who had asked for pen pals and got a cute but curt note saying he had already found one. Jacob was crushed.

J.L., California

EDITOR'S NOTE: Many readers—both children and adults—have asked about the possibility of a regular pen pals page. We currently are exploring the logistics of putting such a department together. We know that a pen pals page would be very popular, so it is something we would like to do.

Discover the total difference from Promise®.

Advanced UltraDry™ Technology means drier skin. And so much more.

Experience the protection of the Promise® Total Care System, the most complete and effective line of incontinence products available today. Designed by a team of health care professionals, the Promise Total Care System uses superabsorbant materials to provide maximum absorption, dryness, containment and odor elimination.

With Promise, you'll get:

- Maximum comfort with our Multi-Strand leg elastic
- Youth briefs through full size - from 17" to 58"
- Best regular design in performance and cost
- Fully disposable briefs and pads - available in winged, fitted or regular style brief (for moderate to heavy capacity) or, pads and cotton pants (for light to heavy capacity)
- An assortment of incontinent care cleansing products
- Delivery to your home

For more information or to receive our free brochure, call **1-800-659-8037** and talk with our trained professionals.

Direct Delivery Services

Your source for Promise® products.

Circle # 230

550

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

[1] *Customer is responsible for a 121-day minimum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.*

[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford
Ford and Lincoln-Mercury Divisions

Circle # 30

SEARCH

Adoptive Parents

I am the adoptive mother of a beautiful, sweet-spirited three-year-old girl who has multiple disabilities as a result of "shaken baby syndrome" at seven months. She has cerebral palsy, developmental delays and a visual impairment. I would like to correspond with other adoptive parents of similar children. Because my daughter has multiple disabilities, I haven't found a support group that meets my needs.

M.W., Alaska

EDITOR'S NOTE: Alaska's Parent Training & Information Center may be able to help you connect with other parents in your area. Contact the Alaska PARENTS Resource Center, 540 International Airport Road, Suite 250, Anchorage, AK 99518, (800) 478-7678.

Infantile Spasms

We are the parents of a beautiful one-year-old son, Eric, who has infantile spasms (hypsarrhythmia EEG pattern), microcephaly and visual disabilities.

Eric was born eight weeks prematurely, but progressed with no apparent problems and came home at 16 days of age. At 31 days, Eric refused his formula, had increased urine output and was extremely fussy. We took him to the emergency room, but doctors found nothing wrong. Our pediatrician was consulted and wanted Eric admitted so she could check him.

While waiting to be admitted, Eric had his first crisis—he began to turn blue around his mouth and a code was called. While being treated, Eric had his first seizure and required ventilation. After two and a half weeks in the hospital and many more seizures, Eric came home again. He was on Phenobarbital and his seizures were controlled—all seemed well again. Despite numerous tests, no cause for the seizures was found.

At five months of age, Eric had a follow-up EEG and hypsarrhythmia was present. He was given two daily injections of ACTH for nine weeks. He is currently on Depakene, and his seizures are pretty well controlled. He is irritable most days, but when a smile is coaxed out of him, it melts your heart.

We are very anxious to talk to other families who have dealt with infantile spasms. Since so little information is available, it is difficult to understand or look to the future. Eric appears "normal." This sometimes leads to heartbreaking comments from well-meaning people.

We would also appreciate suggestions from families with children who have visual disabilities on how to motivate movement and interest in objects and people. We'd like to hear about particular toys that a child with a visual impairment may find interesting.

J.L. & A.L., Nebraska

EDITOR'S NOTE: A free "Toy Resource List" is available from the National Federation of the Blind. Contact NFB POBC, Committee on the Blind Multi-Handicapped Child, 1912 Tracy Road, Northwood, OH 43619, (419) 666-6212.

Two Children With Spina Bifida?

We are parents of a two-year-old daughter who has spina bifida. We also have a three-and-a-half-year-old son. We are considering the possibility of a third child and are weighing all the issues. We are interested in hearing from parents who have two children with spina bifida. Doctors tell us that we have a three-to-five percent chance of having another child with spina bifida, and we would like some insight into what life would be like with two affected children.

D.H. & D.H., Tennessee

Ventilator Dependence

My two-and-a-half-year-old son has been diagnosed as having nemaline myopathy, a form of muscular dystrophy. The muscle weakness throughout his body has resulted in respiratory problems and he is ventilator-dependent.

I am interested in talking with parents who are taking care of a child who is ventilator-dependent at home. How you deal with everyday life?

D.S., Tennessee

Band Heterotropia

My five-year-old daughter has a rare brain disorder called band heterotropia causing an uncontrolled seizure disorder and two-year developmental delay.

I would like to hear from parents of other children with this diagnosis. I have been told there are at least 20 other children with this disorder. I would like to know how other parents cope with their child learning new words and skills, then losing those skills and having to start all over. Since Rene has been taking a new seizure medication, she is doing and learning much more, but we still have to cope with many different seizures. Recently, she has gone from drop-attack seizures only, to drop-attack with complex and absence seizures, startle seizures in her sleep and tonic-clonic seizures requiring oxygen.

On the positive side, Rene just recently learned how to ride a two-wheel bike. That might not seem like a big deal to most people, but with a child like Rene, everything she learns is a big deal.

I would really like to hear from any parents who have a child with band heterotropia. It would be great to talk with someone who is going through similar experiences and who would

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,
Exceptional Parent
magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34H1

Exceptional Parent 12 times a year!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ School: (12 issues) for $30*.
- ❑ 3 Years (36 issues) for $54*.
- ❑ School: 3 Years (36 issues) for $72*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

School _____

Address _____

_____

City _____ State _____ Zip _____

Please allow 4–6 weeks for delivery 34H1

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
First Class Mail Permit No. 241 Denville, NJ

Postage Will Be Paid By Addressee

Exceptional Parent

P.O. Box 3000, Dept. EP
Denville, NJ 07834-9919

You can get a copy of the magazine that helps you parent your child with a disability times a year!!!

That's right,

Exceptional Parent

magazine will bring you the information you want and need monthly!

Look for our new departments:

- Fathers' Voices
- Role Models
- Point of View
- Research

See reverse side for subscription details

understand my frustrations and the fear of not knowing what the future holds.

M.D., Vermont

Low Brain Stem

I am the mother of a seven-year-old son with spina bifida and Arnold-Chiari malformation, Type II. Carl's brain stem goes down to the C-5 vertebra. He also has multiple shunts for hydrocephalus. At age three, he had posterior fossa decompression surgery in which the surgeon enlarged the foreamen magnum, shunted his fourth ventricle, did a laminectomy to the C-3 vertebra and enlarged/expanded the tight fuscia, even grafting on some tissue to allow for expansion.

Carl has had multiple neurological problems as a result of his low brain stem. He has had difficulties managing a variety of food textures, some temporary facial paralysis and speech difficulties. Most recently, he has had episodes of high blood pressure resulting in episodes of high intercranial pressure, profuse sweating, flushing of the face and grunting. Carl is taking a diuretic and medication for high blood pressure. The doctors have ruled out kidney and heart problems and seizures. They believe that these episodes are related to Carl's low brain stem. I am interested in hearing from other parents of children who have spina bifida with this type of symptomatic Arnold-Chiari malformation or other parents of children with brain stem problems similar to Carl's.

Despite all his medical problems, Carl has been able to attend half-days of school. He enjoys school and makes friends easily, but misses many days due to the episodes described above, frequent illness and general lack of stamina.

S.B., Washington

Lipomyelomeningocele

My daughter, 19-month-old Ashlen, was born with spina bifida, type lipomyelomeningocele. My daughter's spina bifida is very unique. Ashlen's spinal cord grew to an unusually long length, escaped her vertebral column, went through a fatty tumor and continued out her back as an appendage. The odd characteristic of Ashlen's lipomyelomeningocele is that it is not midline—it is off to the left side of her lower back.

My daughter had reconstructive surgery shortly after birth and has been able to participate in normal motor activities—walking, running and jumping. Now, however, Ashlen's spinal cord and nerves have begun to get tangled up again. This can cause nerve damage. She has problems walking now, and if untreated, she could lose her ability to walk. Next week, Ashlen is going to have surgery to untether her spinal cord.

Little information is available on lipomyelomeningocele. We don't know how Ashlen will function after this surgery or in the future or whether she will need additional surgeries later. I would like to hear about the experiences of other parents so that I can form an idea of what Ashlen's future may be like.

V.M., Florida

Chromosome XXXXX

I am the physical therapist of a darling 13-year-old girl who has penta-X syndrome (five X chromosomes). We are unsure of what her future holds. Her orthopedist states that he may have to fuse both her elbows due to irregular bony surfaces that are causing inflammation and pain. This seems like a drastic measure to me!

I would love to share information with anyone out there—parents, therapists or physicians—who have contact with an older child with this syndrome.

B.K., California

Kabuki Makeup Syndrome

My three-year-old daughter has been diagnosed with kabuki makeup syndrome. Her doctors have very little information to give us. I have written to every organization I know of, and although I have discovered some limited information, I am more interested in hearing first-hand experiences of other parents. I want to know about typical developmental milestones and difficulties associated with the syndrome.

I have only been able to locate five other children in the United States with this syndrome, and the three that I have been in contact with have kabuki

Now he has a place for everything like everyone else.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

1-800-4-MYDESC

RHAMDEC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2240
MYDESC is a trademark of Rhamdec, Inc.

Circle # 103

ACCESSHOWER + ADJUSTEASE = CLEANING SOLUTION
IT'S SO EASY, IT'S CHILD'S PLAY!

An AccessAble, successful bathtub replacement! Good-looking and barrier-free, **Accesshower's** an easy to do 1-day, no-plumber project!
It's a safe investment—you can even take it with you when you move!

Safe, wet fun in the shower and bath—and it goes to the beach or pool, too!
AdjustEase Washchair's your sensible buck- and back-saver!

ORDER YOUR ACCESSHOWER™ SYSTEM "CLEANING SOLUTION" BY SEPTEMBER 30 TO CLEAN UP 2 MORE WAYS:
❶ SAVE 40% (up to $365!) ON YOUR CHILD'S ADJUSTEASE™ WASHCHAIR!
—PLUS—
❷ GET THE AMAZINGLY ADAPTIVE ORALGIENE™ FAMILY ORAL-CARE SYSTEM FOR ONLY $59.99! (regularly $89.99!)

AccessAble℠
ENVIRONMENTS + PRODUCTS FOR EVERY BODY!
1 800 285 2525
YES, WE CAN FILL 3RD PARTY PURCHASES THROUGH LOCAL DEALERS! JUST CALL US FIRST!
Circle # 9

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438
Haverich
ORTHOPAEDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America.
Steel frame. Duel caliper, drum and coaster brakes available.
Parking brakes standard.
Latest styling and wide choice of colour combinations.
More than 30 specially designed accessories to meet every need.

Circle # 36

SEARCH

makeup syndrome along with other disabilities. My daughter has no other diagnoses.

M.W., New Jersey

Undiagnosed

Our five-year-old daughter remains undiagnosed. Katie appeared normal at birth but had very high bilirubin levels and Rh incompatibility. At nine months of age, after she had failed to meet a number of developmental milestones, we began to look for some answers.

As an infant, Katie always smiled easily; however, she was very irritable at night and had very irregular sleep patterns for her first three and a half years. (Sometimes, she still wakes up to "play" at 2:00 a.m.) Katie sat up at 12 months. She never really crawled, but walked at age three and a half. She has had extensive tests—CAT scans, an EEG, an EKG, an MRI and three genetic evaluations. All the doctors who have evaluated her feel that her cluster of characteristics indicates a syndrome, but they don't know what it is.

Our description of Katie is as follows: She is a very happy, social child. She is petite and has hypotonia, microcephaly and mental retardation. She is non-verbal; we feel that she understands more than she can express. She makes inconsistent eye contact and drools. Katie walks with a wide gait and seems somewhat off balance. She likes to have her hands rubbed and tends to fixate on things she likes such as Disney characters. She loves to look at books and tries to interact with other children.

Katie has been tested for tuberous sclerosis and fragile X syndrome. She has been thought to have Rett syndrome and Williams syndrome. As parents, we have felt that she might have Angelman syndrome but have been told that it is not possible. We would welcome responses from anyone who can help.

D.T. & B.T., Illinois

Telecommunications Corrections/Additions

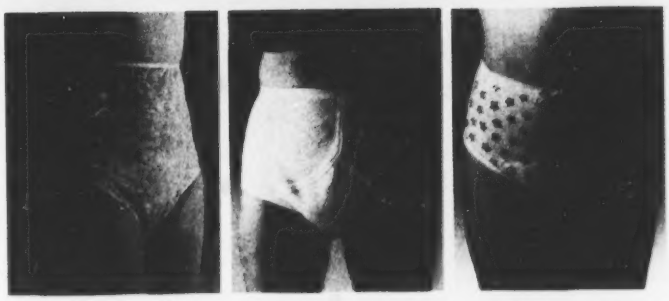
The distribution address of the **ADD-PARENTS** Internet mailing list has been changed. The new address is **majordomo@mv.mv.com**.

An addition to the list of *Disability-Related Electronic Bulletin Boards* is as follows: **ABLE INFORM (Maryland)** (301) 589-3563, up to 9600 bps. *Emphasis on assistive technology and rehabilitation/disability literature. Searchable databases, resource guides, fact sheets.*

The Next Step In Dealing With Incontinence

If incontinence is part of your life, you're not alone.

For millions, it's a fact of life. But now there's a better way to deal with it.



For women and men, girls and boys: Hypersorb looks like activewear, works like incontinence wear.

Now there's Hypersorb,™ a new technology that brings a new level of comfort and confidence to incontinence products.

What's more, it's also reusable, so it brings a new level of economics. And that's not all.

As you can see, it has the fashion of activewear, so it will appeal to everyone from children to seniors.

We know it works; it's been working for years throughout Europe under the brand name Ganmill.

Even uncompressed, it's only 4mm thick, so it can be used in a variety of fashionable designs.

You'll also notice that there's a lot less bulk than you expect in an undergament that works so well.

And it keeps working a long, long time. After multiple washings, its absorbency is still 1000%. Which means it can save you quite a bit of money over disposables.

Even better, this also works for our environment. We use only pure polyester and viscose fibers; add no chemical binders or wood pulp products.

All told, we believe that Hypersorb will work better than whatever you're using now.

But talk is cheap. We back that up with a One-Year Guarantee. Follow instructions, and if Hypersorb doesn't keep working, send it back. We'll give you a new one or your money back.

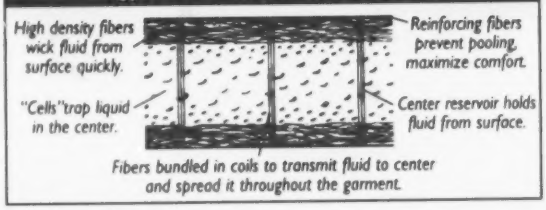
So call, write or fax us. MasterCard, Visa and personal checks are accepted. Do it now.

Because you've got nothing to lose.

And you've got a much better way of dealing with incontinence to gain.

Ganmill
Personal Healthcare & Hygiene

Hypersorb : Why It Works Better.


High density fibers wick fluid from surface quickly.
"Cells" trap liquid in the center.
Reinforcing fibers prevent pooling, maximize comfort.
Center reservoir holds fluid from surface.
Fibers bundled in coils to transmit fluid to center and spread it throughout the garment.

HYPERSORB PATENT PENDING

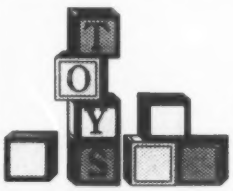
TMI
TECHNOMARKETING INC

307 Bacon Road • Rougemont NC 27572 • (919) 477-1387 • Fax (919) 477-2294

Circle #122

Switch on the Fun With InvoTek Toys

InvoTek toys are the perfect gift for any severely physically involved child. Popular toys for girl and boys of all ages have been modified to be switch accessible. Toys that are presently available include: **Tiger® 2-XL™ Talking Robot, My Little Smart first words™**, and **Tyco® Electric Racing Set**. Order soon to ensure holiday delivery. Limited quantities are available. Call InvoTek for a catalog and pricing.



InvoTek Corporation
700 West 20th Street, ENRC
Fayetteville, AR 72701
1-800-576-6661

Circle # 211

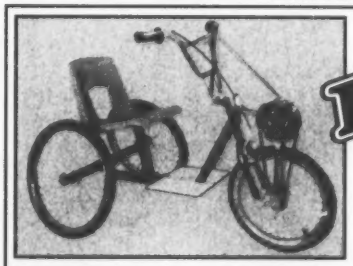
Our Toilet Supports are so adjustable toddlers thru adults can use the same one. We have High Back and Low Back versions. Pommels, urine deflectors, foot rests and smaller seats for young children are available.

Our **NEW** Bath/Shower Chairs are the most adjustable ones made. We have 3 models - an **Elevated**, a **Standard**, and a **Roll-In Shower** chair. Each model has 6 sizes to maximize the time of its use. Your child and you

For a free brochure call or write:

The Adaptive Design Shop
12847 Pt. Pleasant Drive
Fairfax, VA 22033
703-631-1585

Circle # 3



Earn-A-Bike

Yes You Can!

Many models to choose from!

Call Now
1-800-654-9664
Office hours: 8:30 am - 5:00 pm Mon.-Fri. Central Standard Time

CALL NOW FOR A FREE VIDEO INFORMATION KIT.
DON'T FORGET TO ASK ABOUT THE NEW
EARN-A-BIKE PROGRAM.

You can get your therapeutic cycle for FREE!

Rock N' Roll Cycles
P.O. Box 1558 • Levelland, Texas 79336

Circle # 232

Infa-Dent®
Finger Toothbrush and Gum Massager

* **GENTLY CLEANS TEETH**
* **MASSAGES GUMS**
* **EASY TO USE**

Available At Your Nearest Drug Store
Or Call 1(800) 868-8338
Nu-Tec Health Products,™ Inc

Circle # 56

RESPOND

Prader-Willi Syndrome

C.M. (May 1994) is the parent of a three-year-old girl who has been diagnosed with Prader-Willi syndrome. C.M. wanted to contact parents of other children with this disorder—especially parents of children, like her daughter, whose DNA tests have come back negative.

My seven-year-old son, Steven, has Prader-Willi syndrome and shows a chromosomal deletion. However, various sources say that only 50 to 75 percent of individuals with Prader-Willi syndrome show a deletion.

Molecular genetics is another area to explore. Your daughter could possibly have a maternal disomy in which she would have two strands of chromosome 15 from her mother and none from her father. The father's chromosome 15 could have been lost, or may have translocated to another chromosome.

My understanding is that Prader-Willi syndrome can also occur as the result of some sort of brain damage in which the hypothalamus is affected. This would result in symptoms of the syndrome, but it would not be genetic in nature.

I am a parent, not a professional. You need to seek expert advice from a professional who can give you a detailed and more fully accurate account of the various genetic and non-genetic causes of Prader-Willi syndrome.

D.O., North Carolina

Teeth Grinding

A.T. (June 1994) is the mother of nine-year-old Nicole who has been diagnosed with PDD/Autism and bipolar disorder. A.T. hoped to find a solution to Nicole's habit of grinding her teeth. Nicole now has several permanent teeth, and her mother worries that the constant grinding will seriously damage them.

I am an adult who has a problem with teeth grinding. My dentist made me a mouth guard to help me stop.

I also have a friend whose daughter has disabilities that sound similar to Nicole's. Like me, her daughter was fitted with a mouth guard. Now, when she grinds her teeth, they do not touch.

I agree with you that Nicole's teeth will not last if she keeps grinding them. I have had several broken teeth because of grinding. I have been wearing my mouth guard for a year now—I have much less jaw pain, and my teeth are fine.

A.B., South Carolina

☐ My 12-year old son, Adam, was born prematurely. He is developmentally delayed and has attention deficit disorder.

Like Nicole, Adam used to grind his teeth. We never knew what to do about it. Finally, the director of Adam's educational program suggested that we let him have chewy candies such as gummy bears and marshmallows. He explained that Adam probably grinds his teeth because he gets satisfaction from chewing. He believed that using chewy candies would give Adam the same pleasure, so he would gradually stop grinding his teeth.

This solution has worked like a charm. Within a few weeks, Adam had almost completely stopped grinding his teeth. Only occasionally does he still need a marshmallow.

L.S., New York

Benign Congenital Hypotonia

S.C. (April 1994) is the mother of one-year-old Matthew who has fine- and gross-motor delays, speech delays and feeding problems. After initially suspecting hypotonic cerebral palsy, doctors have classified his disorder as "benign congenital hypotonia." S.C. wanted to contact parents of children with similar problems. "During the last two years, I have felt very alone. Outwardly, my son looks like a perfectly normal one-year-old," she wrote. "It is hard for friends and family to understand." She also requested information on learning disabilities or other long-term problems that may be associated with hypotonia.

My three-year-old son, Nathan, was diagnosed with hypotonia at the age of 16 months. Since this diagnosis, I have met a number of people familiar with hypotonia. I met a 35-year-old man and his older brother who were diagnosed with hypotonia as infants, however, one would never know this today. The younger brother has a slight speech impediment, but operates his own flourishing business selling sound systems.

A woman I work with has a daughter who was diagnosed at birth with hypotonia. As an infant, she was fed by G-tube. Now, this child is in a regular fourth-grade classroom. She has excellent reading skills, but receives some remedial help in math.

My son currently receives physical, occupational and speech therapy. Nathan started taking steps by himself at 21 months. His gait is slowly improving. He now can put two syllables together—he says things like "mama," "dada," "purple," "big bird" and "big boy." His fine motor skills have improved considerably.

Intellectually, Nathan exceeds his age level in nonverbal tasks like identifying objects and putting interlocking puzzles together. He understands everything that is spoken. However, I must admit that a year ago, I had my doubts about how much he could comprehend. This was because he was too uncoordinated to follow through with many commands. He may also have experienced some frustrations that prevented him from demonstrating his abilities.

We are a family of five who feel extremely blessed with Nathan; he has more compassion than most children his age and a terrific sense of humor. His prognosis is considered quite good.

It's important to realize that improvements come slowly, so you may not notice them at first. But rest assured that I have only seen and heard of hypotonia improving with therapy.

C.M., Pennsylvania

☐ My three-year-old son was diagnosed with hypotonia at the age of five months. Jon has no head control. He cannot walk, or even sit without maximum support. It is hard to keep him occupied and stimulated at home because his mind is so far ahead of his body. He does not yet talk, but is starting to babble more. I have great hopes that he will talk one day. He understands so much and becomes frustrated at his inability to communicate.

Like you, I have felt isolated and alone. Jon and I belonged to a play

"We were prisoners in our own home."

These were the descriptive words spoken by one mother. Another mother characterized her family as a "*war zone*".

Maybe you, too, can identify as Rebecca's mother describes her daughter ripping her clothes, throwing plants from their pots, and screaming. Sean's mother says he has given himself bloody noses, black eyes, and would cling to people because he was afraid to let go.

In the new Heartspring school video, both mothers speak candidly about their children, their home lives, and what it's been like since they've enrolled their children at Heartspring. Heartspring has opened up a whole new world to these children. A team of specialists, including their parents, develop individualized programs designed to meet the special needs of each child.

Now Sean's mother says, "He's becoming more of an adult ... taking responsibility for himself and doing things for himself that I had previously done for him."

After describing what some parents are still doing for their children, Rebecca's mom summed it up by saying, "I now believe that for all of our children, it doesn't have to be that way."

And it doesn't. If you, too, feel your home is like a prison, call Heartspring today. We can also send you this video so you can learn more about the lives of Rebecca and Sean.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800-835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

group in the neighborhood. After his diagnosis, there were some weeks when I could not bring myself to attend because it hurt to see the other children developing normally. Now, I have stopped comparing Jon to other children.

My husband and I believe strongly in inclusion. We are fortunate that the mothers in our neighborhood include Jon in outings, birthday parties and other activities. He attends preschool and loves it; we have enrolled him in music classes and swimming lessons also.

P.M., Missouri

☐ My six-year-old daughter, Rachel, is also quite hypotonic although she has a working diagnosis of developmental verbal and motor apraxis. Her developmental milestones were all very delayed—she crawled at 12 months, walked at 21 months and gagged on solid food that was not completely puréed until 18 months. At three years, her vocabulary consisted of seven words. (Now, three years later, I can't get her to stop talking!)

I know what you are going through! Rachel is a very pretty, happy child who has always attracted attention. No one could understand why she never answered when asked her name or age; after all, she looked so "normal." I was also criticized by people who told me Rachel would walk if I would only stop carrying her! People just don't understand invisible disabilities.

Your son should probably begin speech therapy now. He probably has weakness in the muscles that control his vocal cords, tongue and lips; you should be prepared for long-term therapy.

Using a computer also helped my daughter's language immensely. Laureate (110 East Spring Street, Winooski, VT 05404, 800/562-6801) has marvelous software to help teach speech and language to very young children.

Learning to use a computer now will also prepare Matthew for school where he may need to use a computer for writing if his fine-motor problems persist. My daughter started with a single switch, then a touch window, and now uses the keyboard and mouse.

Rachel just completed kindergarten. We had a huge battle with the school system to get her into a regular classroom, but even they now agree it was

560

the right placement. This is not to say that all our problems are over. Rachel still has difficulty with sequencing, visual-motor tracking, fine-motor skills and phonics. She gets a lot of private therapy and some additional help in school. On the positive side, she loves to swing and can pump her legs as well as her classmates with whom she loves to play. She rides a two-wheeled bike with training wheels, and can print all the letters and numbers—some better than others! Most importantly, Rachel has shown everyone that when given a chance and some appropriate help, she can accomplish a great deal.

M.S., California

Feeling "Different"

K.M. (June 1994) is the parent of an eight-year-old girl with Down syndrome who has mild retardation and is included in a regular second-grade classroom. Lately K.M.'s daughter has become more aware that she learns more slowly than the other children. She has been "acting out" and engaging in inappropriate behavior. K.M. hoped to find "new approaches to handle discipline in an appropriate manner while helping her to maintain her self-esteem and get in touch with her emotions."

I am also the parent of an eight-year-old daughter with Down syndrome who has mild retardation. Like your daughter, Holly is in inclusion classrooms at the school she attends. Holly has been in some sort of included setting since her preschool years.

We have always dealt with the inclusion classrooms by giving the other children information on a level they can understand. We want them to begin the year with a basic understanding of disabilities and the awareness that we are all different. For example, Holly's kindergarten teacher talked to the class, read them a book about differences and had them "experience" different disabilities (for example, placing socks on their hands, then trying to put a puzzle together). The teacher asked the children to "help" Holly by being patient with her. She told the class that Holly would be able to do everything they could do, but it might take her a little longer.

This past spring our district's special education advisory committee set up a booth at the school fair to allow children from the community to "experience" various disabilities. The comments from the "normal" children were interesting—"Wow, next time I see someone in a wheelchair I will try to help" and "I won't make fun of people with handicaps again."

My point is that I don't think it's your daughter's problem; it's the people around her. If you can give them more knowledge and understanding, they will be more accepting.

We have never seen a lot of "acting out" on Holly's part. I believe it is because the children around her have accepted her for who she is; their acceptance helps her to accept herself. The best thing that has come out of her class learning about disabilities is that Holly feels "special" rather than "different." I agree that you need to handle your daughter's inappropriate behavior now, but perhaps working from both sides will help her.

A.B., Rhode Island

DiGeorge Syndrome

T.A. and J.A. are the parents of a three-year-old boy who has DiGeorge syndrome, a very rare disorder. They have had difficulty finding current information on the syndrome and hoped to correspond with both parents and professionals who might be able to help.

Since my original description of this rare disorder, we have learned that its symptoms can range from severe to mild. Most children with DiGeorge syndrome have a small deletion of chromosome 22 which can be readily identified by a recently developed test.

I would be happy to talk with T.A. and J.A. and provide them with further information. They will also be happy to know that there is a support group for families affected by this disorder—DiGeorge Syndrome Families, c/o Natalie Ward, 27859 Lassen St., Castaic, CA 91384, (805) 294-3623.

Angelo M. DiGeorge, M.D.
Pennsylvania

At Devereux . . .
a helping hand is just a phone call away

1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

ASK THE DOCTOR

by David Hirsch, M.D

Nutrition and growth

Q My six-year-old has cerebral palsy (spastic quadriplegia) and epilepsy. He is nonambulatory and is on Phenobarbital for his seizures. He goes to school and gets his lunch there. We feed him breakfast and dinner at home. He eats table foods that are pureed or chopped finely, and he drinks some milk and juice. He is becoming more difficult to feed. Meals are a great effort, usually taking more than an hour to complete. This is stressful for him and for us. He seems to be developing an aversion to food. He weighs 27 pounds and is 42 inches long. Is there anything else we can do to help him nutritionally?

A dequate nutrition is extremely important for any child and especially for those children with disabilities, who often have special nutritional needs and are at greater risk for developing nutritional problems. Many children with disabilities have physical and/or intellectual impairments that may affect adequate nutritional intake. These include, but are not limited to inability to feed oneself, obtain food independently or make wise food choices; inability to sense thirst or communicate the need for fluids; decreased appetite due to constipation or gastroesophageal reflux (severe "heart-burn") which is common in children with cerebral palsy; incoordination of swallowing or chewing; and/or abnormal reflexes such as tongue thrust (a tendency to push the tongue out when chewing).

Medications, especially anticonvulsants—such as Phenobarbital and many others—can adversely interact with or hinder the proper metabolism of essential nutrients such as vitamin D. Subsequently, this affects the body's ability to utilize calcium.

A child with neurological or physical disabilities needs adequate nutrients to optimize or maintain performance and function. In order for such a child to reach his full potential, he needs nutrients adequate for growth and development.

Growth failure is common in children with cerebral palsy. One cause of growth failure is undernutrition due to lack of adequate calories in daily food intake over a prolonged period of time.

Studies have shown that children with moderate to severe cerebral palsy and growth failure require two to twelve times as long to eat a puréed meal as their peers without disabilities. Mealtimes can be

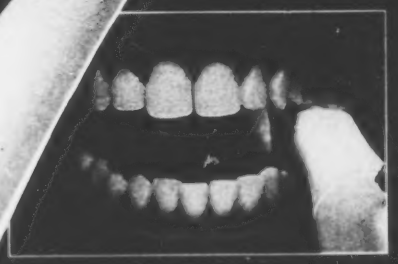
***Ask the Doctor** is a regular department of EXCEPTIONAL PARENT in which questions from readers are answered by David Hirsch, M.D., a board-certified pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses and is affiliated with four Phoenix-area hospitals. He is a member of the Section on Neurology and the Section on Developmental Disabilities of the American Academy of Pediatrics.*

Whenever possible, Dr. Hirsch makes specific suggestions. However, since Dr. Hirsch is responding to letters and will not have personally examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch occasionally mentions specific products or medications, he is doing so to illustrate his suggestions; he is not endorsing any specific products.

*To submit a question to Dr. Hirsch, write or fax: **Ask the Doctor**, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

562

A scientific breakthrough in dental hygiene



THE AUTOMATIC TOOTHBRUSH

ORALGIENE

ADA ACCEPTABLE American Dental Association

ORALGIENE™

The Science of Oral Hygiene

VISA, MC, DISCOVER, AMEX, or send check or money order to:
Oralgiene USA, Inc.
421 North Rodeo Drive, Suite 15114
Beverly Hills, CA 90210

CA & NY Residents add 8.25% sales tax.

Circle # 218

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support

The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 13

exhausting for both child and parent. Prolonged eating time may lead to an aversion to food by your child.

Also frustrating for parents is that the additional time spent feeding a child with a disability leaves less time for other types of interactions with that child and other family members, as well as for household chores or employment responsibilities. Of course, the child may share this frustration. The child also may become frustrated when he or she is fed by many different individuals.

In the case of your son, it seems that the first step should be an assessment of his dietary intake and the changes which need to be made. Your child will need adequate calories and protein—first, for catch-up growth; later, for maintenance of normal growth. Whenever possible, you can add high-calorie, high-nutrient-density foods

One cause of growth failure is undernutrition due to lack of adequate calories in daily food intake over a prolonged period of time.

to the child's diet—foods such as high-fat dairy products (milkshakes, ice cream, butter and eggs), canola oil, peanut butter and wheat germ. The temporary use of these high-fat foods for more rapid weight gain should not cause any long-term detrimental effects. More expensive over-the-counter preparations—such as Ensure, Pediasure and Enrich—have 30 to 60 calories per ounce and can be used as supplements. A multivitamin and mineral supplement, also commercially available, should be added to your son's diet as well. Because of his use of anticonvulsants, it might be appropriate to choose a supplement that has additional vitamin D and calcium. Your pediatrician can tell you the proper dosages for a child of your son's age and weight.

Smaller, more frequent feedings should be attempted. In addition, caregivers should try to make eating as pleasant an experience as possible. It is especially important to have consistency at school—ideally, your son should be fed in the same manner by the same individual every day.

If a short-term trial of this sort of modified diet does not seem to work, a period of enteral supplementation—such as continuous, nighttime nasogastric-tube feeding—can be considered. As always, you should consult your pediatrician for more advice and options.

Nutrition in the child with developmental disabilities is a crucial issue that needs careful and ongoing monitoring. This monitoring requires a multidisciplinary approach utilizing input from health care professionals, educators and therapists who are familiar with your child. If your son's aversion to food makes it difficult to implement necessary changes in his feeding program, a mental health professional may also be able to provide useful assistance.

564

FAMILIAR FACES

*Fifteen-year-old **Rachel Oliver** of South Hill, Virginia cuddles a stuffed bear at bedtime. Rachel, who has autism, is always laughing, smiling and very happy. "She is the joy of our life," says Rachel's mother, Jane.*

*Two-year-old **Chantel Thennes** of Mifflinville, Pennsylvania celebrates a birthday with big sister **Amanda,** who is seven. Chantel has spina bifida. The girls' mother, Debra, recalls the day about a year ago when Amanda asked if a friend's new baby cousin was "special like Chantel." When told that the baby had no special needs, Amanda looked sadly at her friend and said, "I'm sorry the baby is just plain."*

***Evan Siegal,** of Bryn Mawr, Pennsylvania proudly displays a yellow ribbon won at his first horse show. Two-year-old Evan, who has cerebral palsy, loves his therapeutic horseback-riding lessons. Evan is pictured on his favorite pony, Bruno, with riding instructor Maire Guggenheim and great-grandmother Elizabeth Hall.*

***Sherisa May Wallace** tries out her new swim tube during a therapy session at home. She uses the tube in her family's hot tub and at the local pool in Palmer, Alaska. Sherisa is almost three years old and has multiple disabilities.*

*Bath time is **Joseph Glen Seidel's** favorite time of day—he so passionately loves water that he sometimes can't wait to get undressed before getting into the tub. Two-and-a-half-year-old Joey, who has Down syndrome, lives in Ellsworth, Michigan.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent?* Send it to: Readers' Photos, *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

MIC-KEY®

Skin Level Gastrostomy Feeding Kit

Additional Sizes Immediately Available !

Features . . .

- **Designed for improved cosmetic image**
- **Designed for easy placement and exchange**
- **Complete size range for Adults and Pediatric patients**
- **No obturator needed**
- **Available with:**
  - **Patented SECUR-LOCK® Extension Set**
    - **that virtually eliminates disconnects**
    - **with separate feeding and medication ports**
  - **Bolus feeding set for easy bolus feeding**
- **Superior balloon design**
  - **SHUR-FORM® balloon system assures proper inflation.**
- **Stoma measuring device**
  - **Easy to read**
  - **Provides consistent, accurate measurements.**
- **Made of clear medical grade silicone material**

MEDICAL INNOVATIONS CORPORATION
A DIVISION OF BALLARD MEDICAL PRODUCTS

Ballard Medical Products
12050 South Lone Peak Parkway, Draper, Utah
(801) 572-6800 • Fax: (801) 572-6999

For More Information Call: 1- (800) -528-5591

U.S. Patent Nos. 4,759,582 • 4,885,901 • 4,701,163
Other U.S. patents pending and foreign patents issued and pending

Circle #167

Mimi, My Friend

by Anita Stohs

"Where's my friend?" asks three-year-old Christopher as he searches the house for six-year-old Miriam, or "Mimi" as her brothers call her. Mimi is the second of our three children, eighteen months younger than Matthew and three years older than Christopher.

Christopher asks for Mimi when he wakes, and he often falls asleep in her room at bedtime. "Mimi, come play with me!" is his request during much of the day. Christopher misses his sister terribly when she is at school. At the end of the school day, he watches from the window as she gets off the bus. "Mimi's here! Mimi's here!" he cries as she walks through the door. The fact that Miriam was born with Down syndrome means nothing to Christopher—Mimi is his sister and in his own words, "my friend."

Almost Like Twins

Christopher has provided an interesting balance to the family; he interacts in a positive way with both his older brother and with Miriam whose mental age makes her more like his twin than a sister three years older. Because of Christopher, Matthew has a companion in the rough-and-tumble world of little boys, and Miriam is no longer the "baby."

One of the more surprising consequences of adding a third child to the family is the positive relationship that has developed between Miriam and Christopher as both reach a mental age of three years. They seek each other out; then, chattering away as they play together, they come up with projects that often have chaotic consequences.

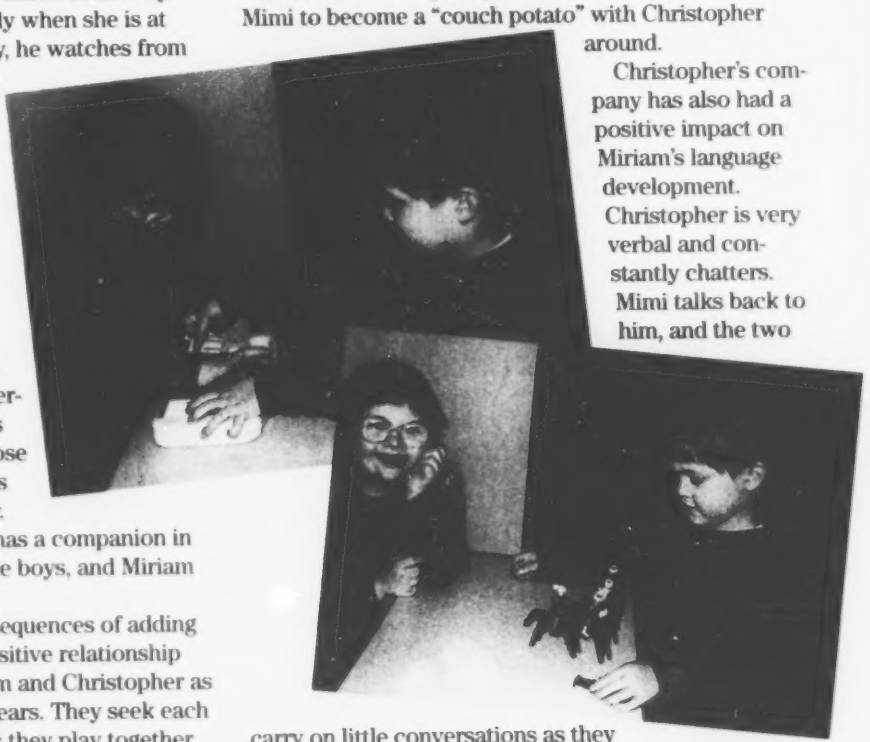
Tonight I found them emptying out Mimi's room. All the toys that could be dragged, pushed or carted had been moved out into the hallway. With Mimi's toy table, sink, refrigerator, cradle, dolls and high chair, they had set up housekeeping in the hall. When I happened upon this scene, the big rocking chair was halfway out of the door—Mimi providing the muscle and Christopher the direction.

Positive Benefits for Both Siblings

When Christopher is not around, Miriam watches television or plays alone, often using different voices to act out events from school, television or videos. A few days ago I heard her yelling outside and discovered she was calling "Lassie."

Christopher helps Mimi learn how to interact with others—to give and take, to share—skills that will help her later in life. When Christopher paints, so does Miriam; if he builds, she builds, too. They do "gymnastics" together and chase each other around the house. Miriam's "running-walk" has improved greatly as she tries to catch her speedy little brother. It's hard for Mimi to become a "couch potato" with Christopher around.

Christopher's company has also had a positive impact on Miriam's language development. Christopher is very verbal and constantly chatters. Mimi talks back to him, and the two carry on little conversations as they work together on their self-appointed tasks throughout the day.



The relationship is hardly one-sided, however. While boys tromp in and out to play with Matthew, they are too old for Christopher. He finds in Miriam a more appropriate playmate. She provides him with an opportunity to learn how to share and work together with another person. "Take turns," says Christopher as he stands with his hands behind his back by the slide, waiting for his sister to go down.

Their concern for each other is touching. "It's okay," says Mimi when Christopher falls down and cries. "Call doctor," she goes on to suggest. If Mimi gets hurt, it is Christopher who comes in to say, "Miriam's crying; she wants Mommy."

The Gap Widens

As Christopher gradually passes Miriam intellectually, I see him beginning to help her with difficult activities like puzzles. In doing so, he is taking the first steps toward becoming a caring, compassionate person. Christopher's first pediatrician, himself the younger brother of a child with a disability, is a good example of the positive way that a younger sibling can develop in a family situation like ours.

For me, there is also a sense of sadness in seeing Christopher advance, doing so easily what Mimi struggles to accomplish. At three, he has already passed her, and the gap will only widen. A parent who is watching a normal child develop can have no illusions about the reality of the sibling's disability; Christopher's development highlights what Mimi is unable to do.

Having Another Child

Deciding to go ahead with "number three" after having a child with a disability is no easy decision. It is one that each couple must make on their own. For most, this involves sifting through available medical and genetic information, as well as considering the social and economic impact that another child will have on the family.

In our case, after consultation with genetic and pediatric specialists, we decided to go ahead and have another child.

A number of factors influenced our decision. First, we thought that a third child would take some of the pressure off of our older son, Matthew—we would be less likely to push him, consciously or unconsciously, to achieve what his sister would be unable to do. Another sibling also meant that Matthew would not be alone in making decisions about Mimi's welfare if we were not alive to do so.

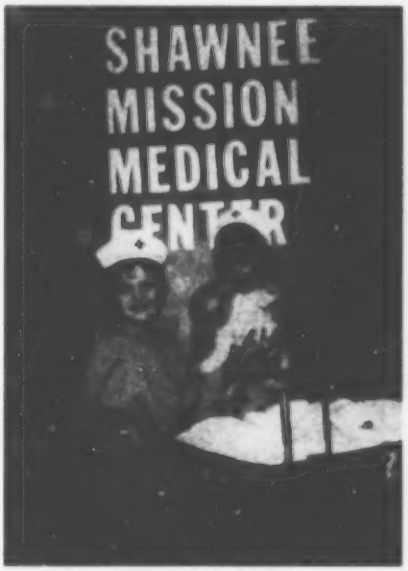
We also thought about the affect a younger sibling could have on Miriam, and on the way we interacted with her. Mimi was becoming the focal point of our lives, a situation that was not good for her or for us. It was hard to fight the temptation to make her the perpetual "baby" of the family. Another child would provide balance for everyone.

The availability of prenatal tests creates another decision for a family in this situation. In our case, we decided to forgo prenatal testing. We had taken Mimi as she was and would do the same with the new baby.

Challenges and Blessings

Caring for two children, both operating on a preschool level, requires incredible energy. After having two "two-year-olds" for the past year, we now have two "three-year-olds"—better, but still a combination that demands constant watching. Sometimes their "big ideas" get out of hand; two "preschoolers" can wreck a room in minutes. And just try catching two kids zooming off on big wheels in opposite directions—a definite logistical problem to say the least!

I know that the time will come when Christopher will need to play with other little boys and develop friendships and interests outside the home. I hope that Miriam will grow as he does. Perhaps the skills that she has learned from her interactions with Christopher will make her better able to play with children she meets at school or in the neighborhood.



Christopher has proved to be a good namesake of the Saint Christopher of legend. In his own way, he "carries" Mimi, as he helps her to grow both socially and intellectually. Mimi is his best playmate, and he is hers. Would that everyone else could see the person, not the disability, as Christopher does with Mimi, his "friend."

Postscript

It is now three years since the evening when I wrote the first part of this article. Miriam is now nine years old; Christopher is six. In many ways, what I had anticipated has happened. Christopher has moved on to a neighborhood gang of little boys who chase each other around the yard and stampede through the house. They generally avoid Mimi—not because she has a disability, but because she is a little girl. When his buddies go home for the day, Christopher plays with his sister.

During the last three years, both Christopher and Mimi have grown socially. In testing this year, Mimi's highest score was in the area of social development. As Christopher also interacts easily with other children, I wonder if his abilities in this domain are a direct result

of his early experiences in learning to work and play with Mimi, his first friend.

At the end of this year, with Christopher in kindergarten and Miriam testing at the five-year-old level academically, both children are learning to read. The two are still "twins," and the result has been a certain amount of rivalry. If one child tries to read flashcards from school, the other has to read them, too. When one sits at the table to write numbers, the other one joins in. As one sibling learned to swim, so did the other. Whatever one learns to do, the other child has to try.

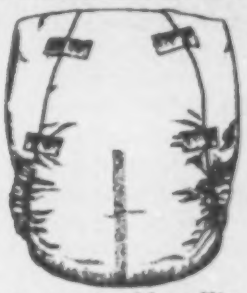
In terms of sibling relationships, it is interesting that now, as the children grow older, Matthew, now 11, is the sibling who interacts best with Miriam. He provides a more age-appropriate role model than does Christopher. Because he is more intellectually mature, he also exhibits a greater ability to see things from Miriam's point of view. Matthew's friends also have become protective of Miriam, reminding their younger brothers and sisters not only to be nice to her, but also to behave well so she doesn't imitate bad habits.

It is hard to predict the long-term effects that a child with a disability has on her siblings; it is equally hard to analyze the influence that siblings have on the child with a disability. In our case, one positive result has been a heightened sense of competition that pushes both Christopher and Miriam to work harder to achieve basic skills. Social skills have also been enhanced for all of the children—through interactions with Christopher and Matthew, Mimi has learned many of the skills required to get along with others; her brothers have developed sensitivity toward their peers and people in the community.

Anita Reith Stohs lives in Shawnee, Kansas with her husband, Eugene, and their three children. She has written a variety of craft and activity books, mainly in the area of religious education. She has also written several articles about disability.

FREE SAMPLE
Attends® Youth Brief

Fits Children 35-75 lbs
– If you're child is too large for baby diapers, but too small for adult briefs.



Send $1.00 postage and handling to receive your free sample and $2.00 coupon!

Name _____
Address _____ Apt. # ____
City _____ State ____ Zip _____

ACCESS MEDICAL SUPPLY
2006 Crown Plaza Drive
Columbus, Ohio 43235
1-800-242-2460

Circle # 228

A Continuum of Service for Children with Special Needs

The Day Hospital

The Day Hospital at Children's Specialized is an innovative, cost-effective option for children and adolescents who require intense rehabilitation. The program allows the child to be cared for at home, overnight, while offering the following daytime services:

- Personalized nursing/therapeutic program
- Close medical supervision
- Interdisciplinary team care
- Up to 10 hours of care (8 a.m. to 6 p.m.) per day, Monday through Friday
- Minimum three hours of therapy per day
- Education
- Transportation

For further information about the CSH Day Hospital contact the CSH Pre-Admissions Coordinator (908) 233-3720/Ext. 361.

CHILDREN'S SPECIALIZED HOSPITAL

CSH-OCEAN
94 Stevens Road
Toms River, NJ 08755
(908) 914-1100

150 New Providence Road
Mountainside, NJ 07092
(908) 233-3720

CSH-Outpatient Center
330 South Avenue
Fanwood, NJ 07023
(908) 233-3720

Circle # 185

The Parent and Professional

Paving the road to parent-professional understanding

Although early intervention policies strongly suggest working partnerships between parents and professionals, parents sometimes perceive busy physicians as insensitive or condescending. While many parents feel enormous gratitude to health care professionals, others have stories to share about health care providers who considered their parental insights as anxiety-ridden exaggerations, gave them faulty information or dwelled so much on the impossible that they forgot about the possible.

Parents who met through the Caring Connection, a parent support group in South Carolina, had these kinds of stories to tell each other. They wanted to share these stories with physicians to help them become better able to provide appropriate health care to children with disabilities and their families. They wanted doctors to learn something about the daily joys and difficulties of raising a child with a disability. Physicians may not be taught family-centered care in medical school; instead, they are often taught to "take charge"—an attitude that can hinder collaboration between parent and professional.

Getting Started

Georgia Murphy, coordinator of the Caring Connection, understood the parents' collective wish to improve the physician-parent relationship. Along with consulting clinical pediatric psychologists Timothy Daugherty, Ph.D., and Conway Saylor, Ph.D., Murphy contacted faculty at the Medical University of South Carolina (MUSC), and made arrangements to have parents speak at noon conferences which are routinely scheduled to enhance the education of pediatrics residents. Residents responded so favorably to the first of these presentations that additional invitations followed—from both MUSC and local colleges.

"To promote understanding and cooperation among physicians, parents of developmentally disabled children and those with chronic health needs, along with the agencies and health care professionals who serve them."
—PAPA mission statement

To make their message more portable and available, the Caring Connection contracted with a professional production crew to create a videotape. Volunteers interviewed nearly 40 parents, grandparents, adult siblings and friends of children with disabilities. Their heart-felt remarks became a half-hour video program entitled *Coping: Through the Eyes of Special Families.*

Getting Funded

With these preliminary experiences, the Caring Connection parents and staff were well-prepared when the state Developmental Disabilities Council announced an intention to fund programs that trained medical professionals, and invited groups to submit proposals. Consulting pediatric psychologists Saylor and Daugherty, both Citadel professors with University resources and considerable grant-writing experience, agreed

PAPA presentations make liberal use of photographs and videos of children with their families, teachers and friends. Such images give audiences a sense of the rhythms of everyday life in these families. In this photo, Alexander Bethke holds down his end of a conversation with Karen Salter.

570

Alliance Program

Home from the hospital: *Dr. Edward Wilson reads to his son Leland. It is 3:00 a.m.—Leland's first night home from the hospital after surgery—and his pain keeps the whole family awake. Leland has cerebral palsy.*

to apply for the grant on behalf of the Caring Connection. The grant was awarded and the Parent and Professional Alliance (PAPA) was born. PAPA hired Christy Bethke to serve as project coordinator, and formed a steering committee that included health care professionals and parents of children with special needs.

The parents and professionals of PAPA, now in their third year, are more active and involved than ever. Last year, more than 400 health care professionals and trainees attended PAPA panel presentations, viewed PAPA videotapes and used PAPA-provided educational materials. Audiences for PAPA presentations ranged from a dozen medical students to more than 100 trainees in health care specialties such as pediatrics, psychiatry, psychology, ophthalmology, pharmacy and dentistry. Private practitioners and faculty also attended PAPA presentations that were given as part of continuing education forums.

Preparing a Presentation

PAPA arranges parent presentations for many different audiences—MUSC students, practicing physicians and other professionals. To plan a presentation at MUSC, for example, Bethke contacts the "training director" of a department—such as pediatrics or ophthalmology—and proposes a specific presentation. Each department's training director, appointed by the department chairperson, is responsible for scheduling speakers for special classes, seminars and lectures. In addition to scheduling PAPA events within their departments, training directors help panelists gear their presentations to the training level and special interests of each audience.

Once a presentation is scheduled, PAPA assembles a group of two to six parent panelists, making a special effort to ensure that the panel reflects the diversity of age, disability and ethnicity in the community. Whenever possible, PAPA chooses parents who have experiences that are especially relevant to the trainees' discipline.

All parent volunteers undergo a training session before their scheduled presentations. At the training session, the PAPA coordinator educates the parent volunteers about the levels of physician training (student, intern, resident, practicing physician) and gives them information about the level and probable needs of their audience.

The training session is also an opportunity to expose the parents to the physician's point of view. Dr. Edward Wilson, MUSC faculty member in ophthalmology and father of a child with special needs, has explained to parents that physicians face disability, suffering and death on a daily basis. Doctors, like parents, find different ways to cope. Some cultivate an objective distance that comes across as clinical and cold, some try to speak only briefly to the parents, and others are unsure about what to say.

During training sessions and presentations, PAPA arranges child care for panel participants. In the past, MUSC occupational therapy trainees and cadets from The Citadel have volunteered as child care workers. It is a system that benefits the volunteers as well—in addition to supplying a needed service, many of these trainees plan to work with children who have disabilities and benefit from their interactions with such children in the child-care setting.

The Presentation

PAPA presentations last from one to two hours. The panels often include one doctoral-level professional who gives a formal presentation about relevant public policy and psychosocial research, and several parents—some live, others on videotape—who offer their stories and lessons to the audience.

Parent panelists describe their child's diagnosis and condition, and talk about good experiences with physicians as well as the unpleasant ones. During the talk, the parent shows pictures of his or her child to the audience. As they speak, presenters may also play background video footage of their children at home.

571

J.J. Hastings enjoys a day in the park with his mon, Sissy.

These images give audiences a flavor of everyday life in a family where one member has special needs.

At the beginning of each presentation, PAPA volunteers distribute handouts for future reference. These handouts may offer information about disabilities, legislation and resources; they may also include poetry or prose that illustrates the parental perspective. A list of local parent support and resource groups are handed out at every presentation. PAPA believes that doctors, from the very beginning, should refer parents to local parent organizations for emotional support and practical information. Some questions can only be answered by another parent.

A question and answer period takes place after all the panelists have spoken. Many times, audience questions lead to further discussion of important issues.

"Nothing But Praise"

In the last two years, PAPA has received positive feedback from parents, trainees and professionals alike. They have won the gratitude of parents and the respect of professionals. Parent Beverly McCarty of Charleston writes, "It is rewarding for me to know that attitudes are being shaped and changed as a direct result of the presentations made by the PAPA parents." Dr. Edward Wilson says, "I have heard nothing but praise from trainees in the pediatrics, physical therapy and ophthalmology [departments]. The use of parent panels and videotape has stimulated much discussion and deeper understanding." Clearly, the efforts of these parents are making an impact in the medical community.

Worth a Thousand Words

PAPA has used video in creative, effective ways. The videotaped segments of each presentation allow medical students and physicians to see important facets of daily life in families with children who have disabilities. Video enables parents to share their stories even if they are unable to attend a presentation. PAPA also records each presentation and adds the tape to their video library. In-state parents and professionals who were unable to attend the presentation can borrow it to view later or make a copy for their own records. (Others may purchase videos from The Citadel, Department of Psychology, 171 Moultrie Street, Charleston, SC 29409, $29.95 each. Ask for a list of available tapes by calling PAPA at 803/953-6351.)

Now, PAPA is using video to spread the word about its program. A recently-completed video, *Parent and Professional Alliance: How to Get Started*, explains PAPA's mission and history. It shows scenes from parent training sessions, parent and professional panels and the videotapes used in presentations.

Parents, agencies or training programs can use the video to learn more about this type of parent-professional collaboration. As parent Nancy Bryant tells doctors in the video, "Parents [can be] very helpful to you if you will ask them. Parents will spend countless hours in the library looking up articles published concerning their child's birth defect... they have a great networking capability. They're willing to share it with you if you're willing to ask." (The video is available from The Citadel, Department of Psychology, 171 Moultrie Street, Charleston, SC 29409, $29.95. A manual to assist groups in implementing this kind of program is due out in the summer of 1995.)

Michelle Annibale enjoys some horseplay with teenage friend, Frances Ott.

Parents interested in implementing a program like PAPA need to know about the resources that are available in their community. Local parent support groups already have extensive network capabilities. They serve the needs of parents; if many parents articulate the need to personally promote family-centered care to the medical community, that local group may have the interest and the resources to help. Established parent support groups may already have professional contacts within the

572

community. This can help parents gain access to the medical education system. The following tips may help as well:

- Any concerned parent can become involved—many roles are possible. A parent can participate in panel discussions, arrange schedules, train volunteers or offer to allow home visits by medical students.
- Participating on a panel can bring up uneasy emotions about one's experiences. A support system should be made available to panelists.
- Money is not essential to pursue this project, but considerable time and commitment are vital. Funding helps, however, by allowing a paid coordinator to arrange training sessions and presentations.
- Members of groups interested in seeking funding can take a course in grant-writing or ask local colleges or universities for assistance.
- Be persistent when making proposals for presentations to medical training programs. Tell training directors about PAPA and note that a number of similar programs have emerged in recent years.
- Use video, as PAPA does, to capture the lives of families in their home. Bethke advises, "Tape children at play with siblings, interacting with friends and professionals, and interview parents where they feel most comfortable. Today's video cameras are easy to use and often can be rented if not owned. If no special editing facilities are available, just hook up two VCRs and make your own edited copies."
- After parents and professionals make presentations, audience evaluation forms should be distributed—a sample evaluation form is available from PAPA. Evaluations give valuable feedback on those aspects of the presentation that were most effective as well as those that need more work.
- Children can also be involved if they are willing and eager to participate.

FAMILIES, PHYSICIANS, AND CHILDREN WITH SPECIAL HEALTH NEEDS: COLLABORATIVE MEDICAL EDUCATION MODELS, a book edited by Rosalyn Darling and Margo Peter, offers a variety of medical education approaches to facilitate communication between the families of children with special health needs and health care professionals. This book will be available in September from EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.

Any parent can do it.

Beverly McCarty, the mother of three children, including twin sons who have autism, says "Any parent can do it. You need not be an experienced speaker. Your life's experiences qualify you. If you've ever sat across the room from, or at a table with, a dozen experts during an IEP meeting, then by comparison, speaking your heart out to a group of professionals won't seem too hard."—*P.Y.*

Kids. Sometimes it seems like they go off to school and leave their memories at home. Of course, lunchboxes and books are easy to replace. But missed medication can lead straight to an emergency. That's why we developed The Reminder, a self-contained, dedicated computer/printer that gives school office personnel an audible alarm and printed reminder and record each and every time a child is scheduled for medication or treatment. So kids can go back to remembering their multiplication tables. If you would like more information on this easy-to-use treatment management system, call us toll-free at ***1-800-553-8167****. We'll send a package to share with schools, physicians and other concerned parents.*

Reminder™
TREATMENT MANAGEMENT SYSTEM

Fishburne International • P.O. Box 706, Asheville, NC 28704

Circle # 233

A Bit of Teenage Savvy

Adolescents with disabilities advise health care providers.

by Peggy Mann Rinehart

The Division of General Pediatrics and Adolescent Health at the University of Minnesota, home of the National Center for Youth with Disabilities (NCYD) and the Center for Children with Chronic Illness and Disability, combines clinical and community-based fellowship training with policy research in general pediatrics, adolescent medicine, ambulatory pediatrics, behavioral and developmental pediatrics and developmental disabilities. The Division is interested in strategies to promote quality health care for children and adolescents. They are also interested in the creation of programs to foster collaboration among the University, community agencies that work with under-served minorities and children, and youth with disabilities and their families.

Among the Division's innovations has been the design and creation of a developmental disabilities rotation for pediatric residents in which parents and community providers serve as teachers. They also are conducting a longitudinal study of resilience in families of children with chronic conditions. And last fall, they went into the community looking for young people who might be interested in serving on a "youth board" designed to provide advice to the Division and its projects. Here's an update.

No one was really sure what the "youth board" would do. Not Division head Robert Blum, M.D., Ph.D.; not project directors Judith Kahn and Bill Malcolm. Not the teenagers who responded to ads and search letters sent to their schools. "We only knew it was a good idea," Malcolm explains. "If your mission is to promote child and adolescent health and to be a part of the communities that serve adolescents, it is a good idea to consult teenagers."

Kahn and Malcolm spent most of September and October recruiting, reviewing applications and conducting interviews. By November, nine young people between the ages of 15 and 19, with visible and invisible disabilities, had become charter members of the Youth Advisory Board. "We're very diverse with respect to gender, race, ethnic identity, ability and geographical background," Malcolm says.

"When I first began, I didn't know what to expect," confesses Shannon McBride, a recent graduate of Cretin-Durham Hall High School. "But I was interested in building leadership skills and going out into the community."

Christine Pui, now a senior at Wayzata High School, already knows she's interested in medicine. This summer, she's working in a research lab. "I found out about the youth board at school," she says.

Teenage Savvy and Unique Experiences

Each member brings a bit of teenage savvy and unique experiences to the board. Dan Thompson, a senior at St. Paul Central High School, is an athlete. He was a member of the Junior Timberwolves, the 1993 national junior wheelchair champions. John Underwood, Jr., graduated from Anoka High School and is actively involved in community theater.

"I was on the Prevention and Risk Reduction Curriculum Review Committee for my school district," recounts 15-year-old Molly Galloway, who starts her junior year at White Bear High school in the fall.

Project director Bill Malcolm leads a meeting of the Youth Advisory Board in the library of the Division of General Pediatrics and Adolescent Health at the University of Minnesota.

"We spent a lot of time talking about sexually transmitted diseases and pregnancy within the schools." Molly is interested in politics and has firsthand knowledge of how hard it can be to create change. "There are so many restrictions," she explains. "[When speaking in schools], you can't show different kinds of birth control or anything like that."

Defining the Board's Role

In May, the youth board attended a workshop to improve their individual leadership skills and help them define the board's role within the

574

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.

AND THEN BACK OUT AGAIN."

At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

P-CAP

CHRYSLER CORPORATION

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Circle #90

Division, but it was not as useful as they had hoped. "It was geared toward student boards that were just starting out," Molly explains. "They kind of said, 'So you've toyed with the idea... well here are some reasons why you should do it.'" This board had already formed and was looking for ways to become involved with a wide range of projects.

During the 1993-94 school year, the board has developed stories for Division newsletters as well as national publications, including an issue of NCYD's *Youth Connections* that was published in *Exceptional Parent* (July 1994).

The board has learned about and provided feedback on several Division research projects designed to improve services for youth with disabilities, youth with HIV/AIDS and youth dealing with substance abuse issues. The board also has evaluated

Youth Advisory Board Members

Alex Blum	*Minnetonka, MN* *Blake High School*
Molly Galloway	*White Bear Lake, MN* *White Bear Lake North High School*
Britta Lindvall	*Richfield, MN* *Blake High School*
Shannon McBride	*West St. Paul, MN* *Cretin-Durham Hall High School*
Christine Pui	*Plymouth, MN* *Wayzata High School*
Tamika Rostron	*Maplewood, MN* *North St. Paul High School*
Dan Thompson	*St. Paul, MN* *St. Paul Central High School*
John Underwood, Jr.	*Anoka, MN* *Anoka High School*
Raquel Zamorano	*Columbia Heights, MN* *Irondale High School*

University and community programs and conferences.

Delving into Health Care Reform

Beyond these typical board functions, the youth board wanted to make a bigger contribution. During a discussion of their own experiences, several members recounted some of the health care experiences common to many adolescents with disabilities and their families:

"I like going to a specialist better than going to regular doctors because I feel like they know a lot about my problems."

"We changed insurance a couple of years ago, and now I have a real nice lady [doctor], but... I never really expect very much."

"I don't really have a doctor. I'm between doctors. They kicked me out of pediatrics, and I haven't found an adult doctor yet."

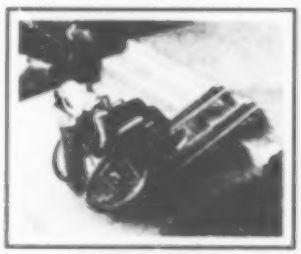
Armed with ambition and experience, the board has decided to write a position paper for the Surgeon General's *Conference on Adolescent Health*.

"This country is working to dramatically change its health care system," Malcolm says. "We feel that a youth perspective needs to be included in order for all sectors of the population to benefit from these changes. Health care reform must be

EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

Look for the Seal of Quality

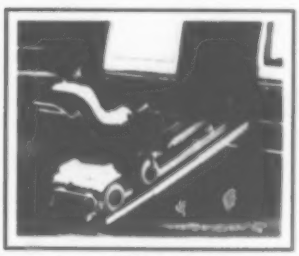


Rollup/3' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle #40

Circle # 40

Board members Christine Pui and Shannon McBride discuss the group's position paper for the Surgeon General's CONFERENCE ON ADOLESCENT HEALTH.

responsive to the needs of youth in terms of the health care system, critical health services and education. Our main intention is to analyze these issues and provide recommendations which would make health care more responsive to our needs."

Risk and Insight

Teenagers like those sitting on the board live with the kinds of "risk behaviors" we read about in the newspapers. Their friends and acquaintances have babies in their teens, experiment with alcohol and other controlled substances and become addicted to gambling. They know kids who have experienced depression, used tobacco or found themselves in violent situations. "These health risks affect youth with disabilities to the same extent that they affect other youth," Malcolm explains.

But these youth board members also have insight. One of their recommendations has been to have teenagers take the lead in designing a relevant innovative health curriculum for high schools.

Looks like they've discovered next year's project.

Peggy Mann Rinehart is director of communications and dissemination for the National Center for Youth With Disabilities and director of dissemination for the Center for Children With Chronic Illness and Disabilities. As the parent of three children, two of whom are deaf and have other chronic conditions, Peggy has developed a keen interest and expertise in the areas of health, chronic illness and disability, social service systems, special education, deaf culture and medical/technical writing.

Peggy is active in various disability movements and serves on many state and national boards and committees including EXCEPTIONAL PARENT's Editorial Advisory Board and the advisory council to the Minnesota State Academies for the Deaf and Blind. She also chairs the consumer subcommittee of the Great Lakes Regional Genetics Group.

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution

- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

Order Now by Calling 1-800-647-8887

Available in Black or Beige

TEMASEK TELEPHONE INC.

21 Airport Blvd. #G., So. San Francisco, CA 94080

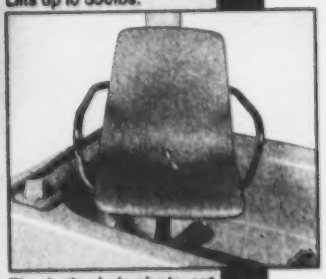
Circle # 202

BATH-MATE ™

Water Powered Bath Lift

The Bath-Mate fits your existing tub without modifications

Water pressure alone supplies the lifting action. Lifts up to 350lbs.



Safe Bathing Promotes more Independence....

The Bath-Mate raises slowly to wheelchair height and lowers within 2 inches of tub bottom.

The bath chair pivots outward for safe transfers.

Optional:

- Seat Belts
- Arm Rest

(800)947-6565

P.O. Box 80095 Ontario, Ca. 91758

Circle # 67

John Kemp

Meeting the Public

John Kemp, Executive Director of the United Cerebral Palsy Associations (UCPA), was interviewed by EXCEPTIONAL PARENT *in June 1994. John, who was born with multiple limb anomalies, grew up in Bismarck, North Dakota and Frankfort, Kentucky where he attended a regular public school and privgte Catholic schools. He graduated from Georgetown University in 1971 and Washburn University Law School in December 1973. After law school, John worked for seven years as an environmental attorney and consultant on disability-related legal issues. From 1982 to 1990, he served in a number of positions at the National Easter Seal Society. He has served in his current position at UCPA since June 1990, the first person with a disability to hold this post.*

Since 1980, John has been married to photographer Sherry Marcy. John enjoys activities with grandson Seth, age five, the son of Sherry's daughter from a previous marriage.

This is the second part of our interview with John; part one appeared in the July 1994 issue of EXCEPTIONAL PARENT.

John shares a moment with President George Bush at a 1992 meeting of the Small Business Legislative Council where both men spoke.

In high school, I was not the only student with a disability. We had moved, and I attended a very small, Catholic high school in Frankfort, Kentucky. The other student with a disability was a boy who'd had polio. He and I would stay up on the third floor of this really old high school. We both walked with great difficulty, up and down those stairs. We would walk up the stairs in the morning and come down when the school day was finished. The cafeteria was in the basement, so someone would run downstairs and get our lunch and bring it up to us. He and I ate lunch alone upstairs. We would stay up there all day.

PART TWO

My older sister was very attractive—a homecoming queen type. I always tried to relate to the guys that she was dating. I wanted to grow up to be like them, but it was very difficult just getting up the courage to talk with girls. I didn't date very much at all. I was the kid with acne, and I thought that was my disability. I thought that was the big reason why girls didn't want to go out with me. My little sister used to tease me about playing connect-the-dots on my face.

When it came time for my senior prom, the only girl I could get a date with was the one girl at the other high school who had a disability. It wasn't that I didn't want to date her because she had a disability. I just thought, "Isn't that a little trite? Isn't that so typical?" I had been such an integrated guy that it just seemed unfair.

College and Law School

When I got to Georgetown University in 1967, my social life changed completely. Maybe my acne cleared up—I have no idea! But, I met a lot of young women who accepted me for who I was, and I had lots of dates.

At that time, there were very few students with disabilities at Georgetown—certainly not many with mobility limitations; there were steps everywhere! The Vietnam war was raging, and I must have been asked a million times if I had acquired my amputations in Vietnam. Sometimes, people would just walk up to me and say, "Vietnam?" And I would say, "No." It was a very difficult time on campuses; it was a wild, crazy period in American history.

I loved my four years at Georgetown. If I were to pick out the four best years of my life, it would have to be my years at Georgetown. I didn't exactly excel in the academic parts of college life, but I was definitely a

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

Circle #18 579

straight-A student when it came to the social aspects. My dad didn't quite buy that argument, by the way. Not at all!

I started out in pre-med, and in the first two weeks, I was taking classes that were so far beyond me that I had to get out. I was taking physics, chemistry and some exotic math class. I was just on the wrong track. In the first semester, I changed my major to American political history.

I graduated from Georgetown in 1971 and decided to go to law school. I went to law school in Topeka, Kansas. Life was very different in Topeka. In Washington, DC, I could get a date whenever I wanted one. But in Topeka, I just couldn't seem to bump into anybody that I really liked. Finally, I got to know a woman who was living in the same apartment building and asked her out to dinner. She said, "I hate to say this to you, but I can't go out with you because you're handicapped."

John chats with General Colin Powell and Senator Phil Gramm of Texas at a reception to honor 1991 recipients of the Horatio Alger Award. The annual awards recognize individuals who have demonstrated the ability to overcome adversity and make a positive contribution to American society. Photo: Horatio Alger Association.

I must have been very naive, but I just didn't believe that people would be rude enough to say something like that, especially not to *me!* That was the beginning of a rough two and a half years. I decided I was going to get out of Topeka as quickly as I could. I went through summer school and graduated in December of 1973. I haven't been back to Topeka since the day I graduated.

Meeting the Public

Society still has a long way to go. For example, I just got back last night from New Mexico—when I can, I like to go to Santa Fe and just relax. In Santa Fe, I went to the club on the top floor of a hotel to have a drink. The club had one step at the entrance, and I was with a guy who was in a wheelchair. So, I walked in and asked a man working there if there was a ramp available. The guy said, "Handicapped people are not allowed here."

I looked at him and said, "Don't you ever say that to anyone again! I can't believe in 1994, that you would dare to say to me that handicapped people are not allowed here." I am going to file an ADA charge against the hotel unless they tell me that they have developed an appropriate plan of action to deal with this access problem in thirty days.

Children deal with disabilities better than adults. Children confront us; adults avoid us. I don't mind answering honest questions—"What happened to your hands; why do you limp?" Children's questions are sincere and practical. They want to know if I can drive a car, play basketball and write; a kid might ask, "How do you go to the bathroom?"

If a child stops me in a supermarket and asks me questions, his mother and father are usually horrified. So they walk up and grab Timmy and put a stop to his interactions with me. I use this example to explain the difference between a handicap and a disability—I have a disability; mom or dad has a handicap; Timmy is doing fine.

Adults, on the other hand, will see me walking down the street, and at a distance of about 30 feet, they will start whistling or humming and looking everywhere else but at me. They don't want to stare and make me feel uncomfortable, but their avoidance basically eliminates me from the face of the earth. Finally, I figured out that when these people got about three steps past me, they usually turned around to check me out. Now, when I walk by someone who is looking all around the place and won't look at me, I always count off three steps after we pass, then turn around to catch the person sneaking a peek at me. And I wave.

I make these people feel uncomfortable on purpose because those of us with disabilities know very well that we look different. We have mirrors in our homes; we go past plate glass windows. We know what we look like. For people to use the fact that we look different as a basis for completely disassociating themselves from us is a subtle form of discrimination.

Younger adults who have attended schools where children with disabilities were mainstreamed are much more comfortable with us. Studies have shown this. They have learned that disability is not a seriously distinguishing feature; it is just another characteristic.

When I meet new people, I always have to initiate the handshake because they don't know quite what to do. Sometimes, they don't grab my clamp; they grab my arm or my shoulder, or they start bowing like we are in Japan—they freak out. Seeing how well people

580

handle that introduction and handshake has become my little barometer for how "cool" a person is.

Taking Risks

I think confidence is instilled at an early age. Confidence involves being truthful with yourself about your own abilities. Sometimes, I venture into things that I don't succeed at, and the sooner I figure out I can't do something or can't do it well, the better off I am. This is not to say that people shouldn't try to do things that they can't do. But sometimes, I have to admit that I am not very good at certain things. I think we all need to understand our strengths and build on them.

My overall advice to parents is to let your kids take some risks. All too often, parents are very worried about allowing their children to venture into new areas. They want to protect them from humiliation, teasing and failure, but that isn't the real world. In the real world, they will have to learn how to deal with the discrimination that will happen to them, and they will have to learn how to cope with people who are jerks. Parents have to be able to put that into perspective for their kids, but they also have to let their kids take some risks. That's probably the hardest thing in the world for parents.

- Remote hand control calls the Handi-Move to your bedside.
- Patented gripping system assures a safe, secure fit.
- Shoulder strength not needed.
- Leaves your seat unobstructed.
- Choice of overhead track or free-standing movable unit.
- Streamlined design permits lifting even where the ceiling is low.
- Rugged construction and 2-year warranty.

handi-move PATENTED
982 Route 1–Pine Island, NY 10969
(800) 724-5305

Circle # 35

Empowering Individuals to Share Their God-given Gifts with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

Circle # 75

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

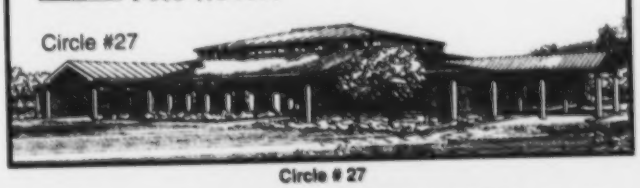
Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27



Circle # 27

Dental Care for Children with Disabilities

Preventing Dental Disease with Daily Oral Care

by Steven P. Perlman

Every child can have healthy teeth and gums. Children with disabilities are no exception. This series of articles will explain some important facts about dental disease and its prevention, focusing on the particular needs of children with disabilities. Future articles will deal with a number of topics including special techniques for daily oral care, common pediatric dental problems and appropriate methods of behavior management during visits to dental professionals.

Dr. Steve Perlman shares a moment with young patient José Jimenez.

PART ONE

Good oral health is an important part of a child's total health. Children with good strong teeth are able to chew a wider variety of foods for healthy nutrition. Healthy teeth aid in speech development by helping children make the proper sounds for speaking clearly. And clean, healthy-looking teeth help children look better and feel better about themselves.

With all the medical, nutritional and emotional needs of children with disabilities, it can be hard for parents to find time for proper daily oral care. Getting a child to the dental office can be difficult, too. But preventive care now can spare the child unnecessary pain and costly dental procedures later.

Prevention with daily oral care

Dental problems can be prevented before they start. That means cleaning the teeth at home every day. Daily brushing and flossing remove plaque, the primary cause of tooth decay. Plaque is a sticky, colorless film of bacteria that constantly forms on the teeth. When food particles, especially from sugary foods, stick to the teeth, the bacteria use the food to produce acids

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to maintaining a private practice in Lynn, Massachusetts, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their "Special Athletes, Special Smiles" program. Dr. Perlman lives in Swampscott, Massachusetts with his family.

582

which cause cavities. If plaque is not removed every day, it can lead to gum disease; and gum disease, if left untreated, can lead to tooth loss—all of which could be painful for the child.

Although daily oral care is a necessity, it should be a pleasant experience as well. Even if the child can't brush and floss properly, letting the child play at cleaning a little when you're finished can add to the fun.

If possible, children should clean their own teeth. You can explain why daily brushing and flossing are important and show a child how to do it. By placing your hand over the child's hand, you can guide the child through each step.

Some children will be unable to clean their own teeth, however. In such cases, the parent must do the cleaning.

Where should you do it?

Daily oral care can be performed in any well-lit room that is convenient. If the child is in a wheelchair, the kitchen might be ideal. If the child is in bed, that's okay, too. Have the child sit up. Then let the child sip water from a glass through a straw and rinse out in a basin. The best place for daily oral care is a place where the child is most comfortable, or where you are able to give the best care.

Positions

There are a number of positions you can use to clean the child's teeth. In any position, it's important to support the child's head. Be careful to avoid choking or gagging if the child's head is tilted back. It is also important for you to be able to see what you are doing and easily manipulate dental floss and brush. Ask your dental professional to recommend the safest, most comfortable position for your child.

Wheelchair
Stand behind the wheelchair. Use your arm to brace the child's head against the chair or against your body. Use a pillow for the child's comfort.

Or sit behind the wheelchair. Remember to lock the chair wheels first, then tilt the chair back into your lap.

continued on next page

Special Children are at Greater Risk

There are a number of reasons why children with disabilities are often more prone to dental disease.

Oral conditions: Some genetic disorders or very high fevers in very young children can cause defects in tooth enamel that make the enamel prone to decay. Congenitally missing teeth and teeth that do not align properly are frequently seen in children with cleft palates and other craniofacial disorders. Gum problems often occur in children with Down syndrome.

Physical limitations: Children who cannot chew or move their tongues properly cannot benefit from the natural cleaning action of the tongue, cheek and lip muscles. Children with disabilities, especially those with poor motor coordination—such as those with spinal cord injuries, muscular dystrophy or cerebral palsy—may not be able to clean their own teeth or may not be able to use the usual brushing and flossing methods.

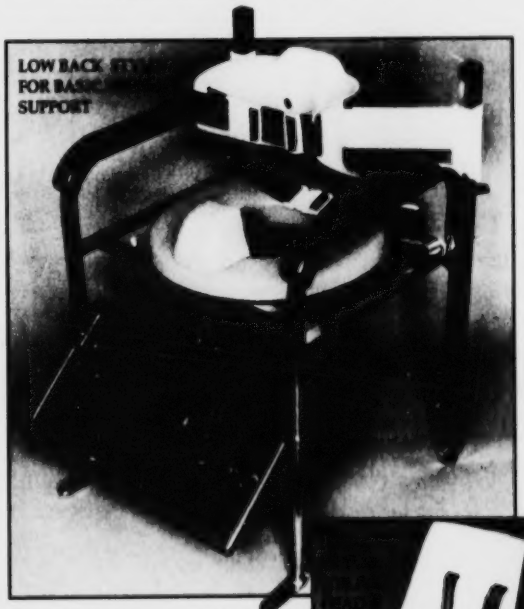
Special diets: Children who have difficulty chewing and swallowing may often eat puréed foods which tend to stick to their teeth. Frequent eating of sugary foods or sleeping with a bottle of formula, milk or juice can increase the chances of tooth decay. Children who need help drinking may drink less fluid than other children, so they don't have enough fluids in their mouth to help wash food particles off of their teeth.

Medications: A number of medications that may be used more frequently by children with disabilities can lead to increased risk of dental disease. *Medications that use syrup or sugar* to sweeten the taste can cause tooth decay if used over a long period of time. Some *seizure medications* may cause the gums to bleed or become enlarged. Excessive gum growth can interfere with chewing and speech; it can also lead to gum disease. *Sedatives, barbiturates, antihistamines and drugs used for muscle control* may reduce the flow of saliva. With less saliva, there is less cleansing action to help protect the teeth against cavities. *Aspirin*, taken in large doses and dissolved in the mouth before swallowing, can provide an acidic environment that fosters tooth decay. Some *antibiotics* should be prescribed with caution because they can stain or discolor newly erupting teeth.

583

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet



The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

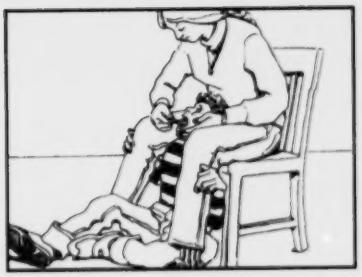
Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 11

Sitting on floor
The child sits on floor; you sit behind the child on a chair. The child leans his or her head against your knees. If the child is uncooperative or uncontrollable, you can place your legs over the child's arms to keep him or her still.

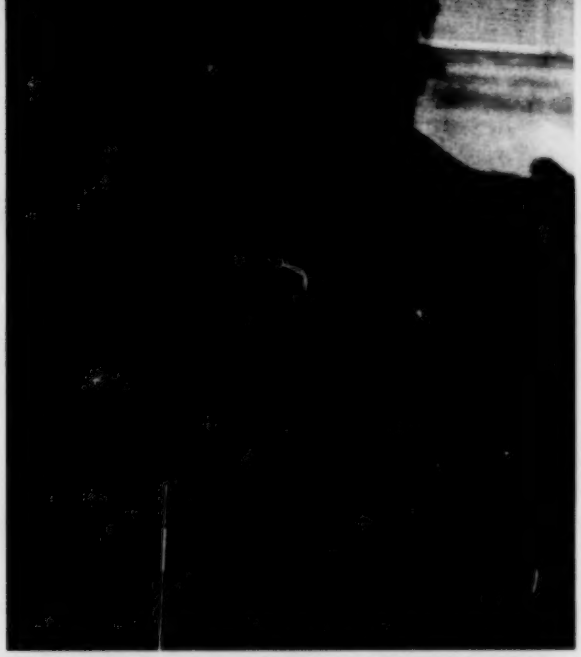


Lying on floor
The child lies on the floor with his or her head on a pillow. You kneel behind the child's head. You can use your arm to hold the child still.

Lying on bed or sofa
The child lies on a bed or sofa with his or her head in your lap. Support the child's head and shoulders with your arm.

If the child is uncooperative or uncontrollable a second person can hold his or her hands or feet as needed.

Beanbag Chair
For a child who has difficulty sitting up straight, a beanbag chair may let the child relax without fear of falling. You should be in the same position as for bed or sofa.



Raul's mom learns oral hygiene techniques that she can use for daily oral care at home. Nine-year-old Raul has a progressive, neuromuscular disease.

This article has been adapted with permission from materials originally published by Johnson & Johnson Dental Care Company.

Home Away From Home

Quality care in a state-of-the-art medically oriented, yet home-like, facility for chronically ill infants, children, and young adults. A one of a kind program staffed by doctors, nurses, therapists, and teachers. If you are thinking about having your loved one cared for outside your home, consider Hacienda de los Angeles with 26 years of experience helping families and their chronically ill family members. Hacienda is located in a semi-rural setting bordered by beautiful South Mountain Park, yet is less than five minutes from the Owens Medical Center.

Hacienda's comprehensive program offers:

- Specialized care for individuals with tracheostomies and those who are ventilator dependent.
- A new facility staffed by professional yet caring employees.
- Open door 24-hour visitation.
- Physician services and round-the-clock nursing care.
- Twenty-four hour respiratory therapy.
- In-house physical, occupational, and speech therapy.
- Nutritional services by a certified nutritionist.
- On-grounds and public school based educational services.
- Private and semi-private rooms.
- Individualized programming designed to allow your family member to reach his/her full potential.
- In-house specialized equipment construction and equipment adaptation.
- Transportation in specially equipped vehicles.

Hacienda de los Angeles, Inc.

In Special Lives, We Make A Difference
1402 East South Mountain, Phoenix, AZ 85040
(602) 243-4231
William J. Timmons, Executive Director

Circle # 199

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle # 26

PROTECTION PANTS

Swimsuit Diapers

Prevents Embarrassing Pool Accidents
Soft, lightweight, outer layer with wick-away inner lining. Tapered design provides protection under a regular swimsuit.

INFANTS ($9.95)
S, M,L, XL, SL
YOUTH ($14.95)
4/5, 6/7, 8/9, 10/11, 12/13,14/15
ADULT ($17.95)
S, M, L, XL

Dry Night Pants

Keeps Outer Clothing or Bedding Dry
Reusable, comfortable pants offer wetness protection. Waterproof knit outer layer with super absorbent inner pad. Holds one cup liquid.

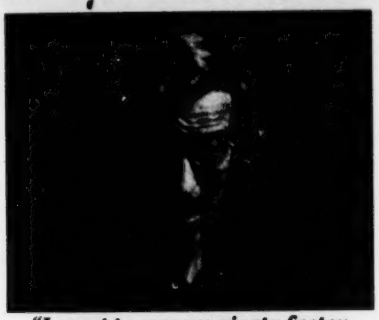
YOUTH ($18.95)
2/3, 4/5, 6/7, 8/9, 10/11, 12/13, 14/15
ADULT ($21.95)
S, M, L, XL

Shipping $3.95
Visa/MC Accepted
Ask for free catalog

Family Clubhouse
6 Chiles Ave.
Asheville, NC 28803
1-800-876-1574

Circle # 174

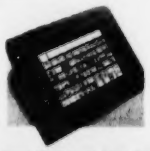
You Asked DynaVox To Do Even More...



"I want to communicate faster with my associates."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at **1-800-344-1778.**



We Hear You.

TECHNOLOGY INC.

Circle # 68

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

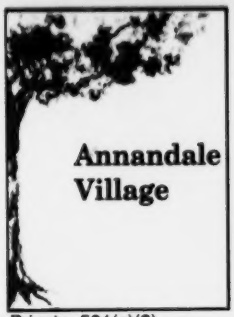
HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

School Directory



Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.
- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710

BEAT THE HEAT!
- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy

800-795-2392

DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

Made in USA Pat. 5168889 *Providing Comfort to Those Who Want It!*

Fathers are Caregivers Too!

by Steve Fischer

When the doctor walked into the room, his intense, focused eyes already communicated the message that his voice was about to deliver. The words he so mechanically began to speak did not come as a surprise. My daughter was extremely sick. Medical science had yet to determine the cause of the illness that had resulted in her being born with profound retardation, cerebral palsy and many other problems. I do not remember much of that day—I believe that the mind protects us by somehow clouding the details of extremely traumatic events. But I remember one peculiar detail that has since become a recurring feature of my encounters with the medical establishment.

When the physician walked in to deliver the message that day, he looked squarely into my wife's eyes. Even though my wife and I were sitting side by side on a chair-turned-hospital-bed, his eyes never made contact with mine. I surely can empathize with the physician, who clearly recognized the pain in my beautiful wife's eyes. But I too was in a state of complete emotional collapse. This physician's body language seemed to convey one of two messages—either that I was not hurting, or that I should simply "take it like a man."

[Above] Steve Fischer with four-year-old Payton; [Left] Payton Fischer celebrates her fourth birthday with family and friends.

Steve Fischer lives in Plano, Texas with his wife, Melanie, and three children, seven-year-old Brittany, four-year-old Payton and five-month-old Anna. Steve works for Texas Instruments. Melanie, a registered nurse, is executive director of PeDiNursing, a private-duty nursing service specializing in home care for children with special needs. Melanie and Steve began this company after the birth of Payton, who has multiple disabilities.

I have to believe that this extremely capable doctor did not treat me this way with any degree of premeditation. Rather, he avoided both eye contact and dialogue out of conditioning. While the mother-child relationship is undeniably powerful, health care providers have been slow to recognize the equally powerful bonds between father and child. I have spent countless nights with grieving fathers over seemingly endless cups of coffee; many of my brothers are hurting and have few outlets to express their emotions.

We are all at different places along the road to acceptance of the various challenges we face. Wherever we are, however, the important role we play in our children's lives should be acknowledged and respected. I readily admit that my wife assumes the greater portion of the day-to-day care of our child. However, I am also a caregiver in my little angel's life and deserve the consideration medical professionals give to my wife.

It has been interesting to note those aspects of a child's care that physicians seem to automatically assign to each parent—and it has been equally interesting to observe their reactions when I have dared to question these assumptions. Mothers are invited to support groups, asked to grant permission for various tests and called to conferences considering the appropriateness of do-not-resuscitate orders. Fathers are relegated to handling paperwork.

We have a long way to go in educating our health

587

care providers about the emotional needs of fathers who have children with disabilities. We fathers must take the lead in educating medical professionals and advocating for ourselves. We must support, encourage and share with each other. We must remind our health care providers that fathers are caregivers, too.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

FREE SAMPLES

WOODBURY PRODUCTS
PRESENTS
Rejoice for CHILDREN

MAXIMUM PROTECTION FOR INCONTINENCE AND BED WETTING

- Innovative two-piece design that combines cotton underwear with an ultra thin high capacity liner and offers maximum protection without traditional diaper bulk.
- Pull-up briefs and side-closing underwear styles that fit discreetly under clothing.

- Advanced absorbency technology in liners keeps your child dry and comfortable. A.S.A.P. TECHNOLOGY
- Easy to change

To order, Call **1-800-777-1111**
Toll-free - 24 Hours
Woodbury Products Inc. 4410 Austin Boulevard
Dept. 250 Island Park, New York 11558

FREE SAMPLES

Circle # 237

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop
P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

☐ I am interested in community involvement. Please send more information about Civitan service clubs in my community.

☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name _____

Address _____

City/State/Zip _____

Telephone Number ( ) _____

CIVITAN INTERNATIONAL P.O. BOX 130220, BIRMINGHAM, AL 35213. (800) CIVITAN

Circle # 186

Special Bathrooms

by Linda Nitteberg

A poorly-designed bathroom often results in a somewhat less than user-friendly environment for a child with a disability. This article describes adaptations that can make a bathroom more accommodating for the child with a disability and for other family members as well.

When planning a bathroom project, the first concern should be safety. A child should never be left unattended in the bathroom. Children need to learn that the bathroom is not a place to play. At an early age, children should be made aware of the possibility of household accidents and taught how such accidents may be prevented.

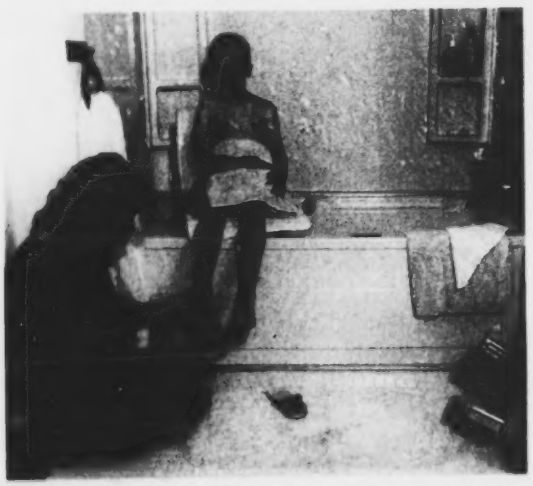
Space requirements

It is important to remember that little children grow into big children. As children grow, they become heavier, their adaptive equipment becomes larger and they require more space.

For many children, growing older means they will be able to perform more tasks independently. But the nature of some disabilities may make it more difficult for some children to develop independent self-care skills—regardless of age. It is important for parents and designers to communicate with doctors, physical therapists and occupational therapists so these factors can be taken into account before any remodeling project is undertaken.

In planning for space needs, it may be helpful to sort your child's activities of daily living into three categories: 1) activities your child can do independently, without difficulty or assistance; 2) activities the child can perform with difficulty and/or minimal assistance; and 3) activities the child can accomplish only with great difficulty or complete assistance.

Special bathrooms need to be designed with adequate clearances. The "three-four-five rule" is an easy way to remember the most important distances. If a person in a wheelchair is to use the bathroom, it should have three-foot (36″) doorways, four-foot (48″) halls (leading to the bathroom) and "aisles" (the space between one wall and an object such as the toilet or sink), and a five-foot (60″) turning radius. With these clearances, the space should accommodate an average, full-sized wheelchair and will allow a caregiver to move alongside the child as needed. The five-foot turning radius will allow a wheelchair to turn around easily.



The DIGNITY BATH, with a built-in, water-powered seat lift, gently lowers and raises the child without using electricity. It can be installed in any home without major reorganization of plumbing. Lap belts are also available. Electric Mobility, Sewell, NJ.

If diapering is a concern, a space should be designed for this activity. One idea is to incorporate a fold-down changing table. Be sure to provide for nearby storage of diapers and supplies.

Storage

Storage space is an important issue in the design of any bathroom. The design of storage space should consider the needs of each family member who will be using the bathroom. You may want to consider the storage of hygiene and health-care items such as medications, IV supplies, feeding supplies, catheter and enema equipment, diapering supplies and exercise equipment (for example, if the child does therapeutic activities such as range-of-motion exercises and needs storage for items like small weights).

It is also important to store items such as medications, razors, makeup and cleaning supplies separately and out of the child's reach. Consider using locking devices on cabinets or drawers that contain these types of products.

Products

Depending on the child's abilities and needs, a range of special products may be useful:

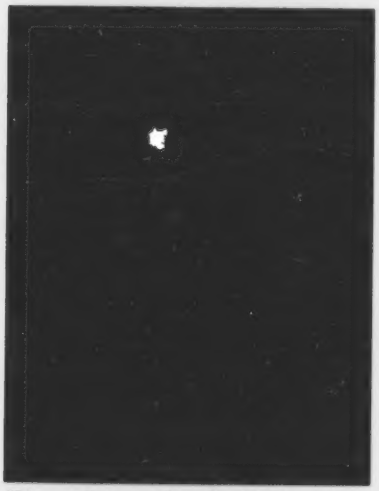
• *Grab bars* should be carefully placed at the entry to all showers and bath tubs. They must be installed according to manufacturer's instructions—preferably by a carpenter. Make sure that there is adequate wood backing behind sheet rock to securely anchor the bars. Behind the wall, bracing can be installed at heights sufficient for current and future needs.

As your child grows, you can move the grab bars higher. Keep in mind that most adults like their grab bars placed 33 to 36 inches

589

above the finished floor. Never use a grab bar as a towel bar (to avoid grabbing for an unstable towel in place of the grab bar or vice versa).

• *Scald-resistant faucets* should be installed in all bathrooms used by children. Most manufacturers make a pressure-balance mechanism and some offer thermostatic control. Most faucet users who have difficulties with grip or strength prefer styles with long, lever handles. There are a few faucets on the market that can be operated without even a touch. These may be ideal for individuals who have severe fine-motor or hand-strength limitations.



Flipper doors make wheelchair access easy; materials can be found in any hardware store. Fold-down grab bars surrounding the Universal-Rundle Toilet (Universal-Rundle, New Castle, PA) are included on a multi-track system from Pressalit that accommodates grab bars, benches and a wall-hung sink. This system allows all items to be adjusted from left to right and up and down. Easy-grip lever handles on sink (ROHL, Costa Mesa, CA 92626).

• *Tub and shower controls* should be positioned near the entrance to the tub or shower, out of the water stream. This allows for added safety. It also allows the caregiver to operate the controls without getting wet.

• A *hand-held shower on a pole* can be useful. The pole, which resembles a vertically-attached towel bar, connects the shower head to a sliding piece that allows the unit to be positioned at the right height for any user. Because the shower head is detachable, rinsing is much easier. It also comes in handy for cleaning the tub or shower.

• *Shower doors* come in a variety of styles. Some have no track on the top or bottom. Consider using a non-glass enclosure for safety.

• *Fold-down shower benches* should be considered for all showers. A bench provides a place for the person being cleaned to sit, an opportunity to rest if fatigued and an easier way to wash one's feet or shave one's legs. Look for a bench that offers the size and support needed. As with grab bars, proper installation into solid-wood bracing is essential.

Electrical outlets

Safety is a primary concern when electrical outlets are being considered. *Ground fault circuit interrupt (GFCI) outlets* protect against electrocution by deadening electrical appliances upon contact with water. *Childproof outlets* are secured behind a plastic cover when not in use. *Grounded switches* are connected to an underground system that protects electrical appliances in the event of a power surge or outage. For added safety, *shatterproof light fixtures* are also strongly recommended.

Flooring

Certain non-slip flooring such as vinyl, linoleum and certain ceramic tiles may be installed to increase safety. Rugs should not be used. Carpets are hard to clean and difficult for wheelchair users to maneuver on. Throw rugs are likely to slide around and could get in the way of canes or walkers.

Additional resources for design assistance:

The National Easter Seal Society (230 West Monroe St., Suite 1800, Chicago, IL 60606, 312/726-6200) offers a free, nine-page brochure that includes accessibility checklists and design ideas. Ask for *Easy-Access Housing for Easier Living.* Send a self-addressed, stamped envelope with your request.

Fold-down shower bench offers a place to sit for easier washing, manufactured by Pressalit in Europe. Call Pressalit at 800/346-2380 for more information.

The National Kitchen and Bath Association (NKBA, 687 Willow Grove St., Hackettstown, NJ 07840, (800) 367-6522) can provide lists of certified designers and rules for kitchen and bath design. (Keep in mind, however, that some rules may not apply to certain disabilities.)

Linda Nitteberg, CKD, is a general contractor, designer and the owner of CONCEPTS KITCHENS AND BATHS PLUS.

Linda has been a long-time advocate for the rights of individuals with disabilities. She is a regular speaker at design classes and teaches at NKBA national conferences. Linda, herself a wheelchair user, brings a unique mixture of expertise and personal experience to the topic of accessible and adaptive design. Readers are invited to contact her at Concepts Kitchens and Baths Plus, 466 Meridian Ave., San Jose, CA 95126.

590

Manufacturers of Bathroom Access Aids

Key

Bath items manufactured by these companies are indicated by the following numerical codes:

1. grab bars, tub rails
2. accessible showers
3. adapted bathtubs
4. seats, benches, chairs for shower; or tub transfer seats
5. bathtub lifts
6. adaptive toilets, commodes, portable commodes
7. toilet seats, supports, accessories
8. adaptive sinks
9. faucets, temperature-control faucets, fixtures, handheld showers, accessories
10. whirlpool baths, hydrotherapy devices

AccessAble Environments *1, 2, 4, 5, 6, 7, 9*
111 Cedar St
New Rochelle, NY 10801
(914) 632-0177
See ad on page 12

Accessibility Design Associates *1, 5, 9*
1711 Old Freehold Rd
Toms River, NJ 08755
(908) 505-0928

Access Industries *5*
4001 E 138th St
Grandview, MO 64030
(800) 925-3100

ACTIVEAID *4, 6*
One Activeaid Rd
PO Box 359
Redwood Falls
MN 56283-0359
(800) 533-5330

adaptAbility *2*
PO Box 515
Colchester, CT 06415-0515
(800) 288-9941

Adaptive Design Shop *4, 7*
12847 Point Pleasant Drive
Fairfax, VA 22033
(703) 631-1585
See ad on page 14

Al-Len Pattern *9*
1931 Perry Hwy
Fredonia, PA 16124
(412) 475-3708

Alsons Corporation *9*
42 Union St
Hillsdale, MI 49242
(800) 421-0001

American Bidet *7*
Box 1500
Hollywood, FL 33022
(305) 983-3333

American Standard *9*
1 Centennial Ave
PO Box 6820
Piscataway, NJ 08855
(800) 442-1902
See ad on page 5

Anaco *10*
909 5th Ave, NE
Brainerd, MN 56401
(218) 829-8488

Andermac *7*
2626 Live Oak Hwy
Yuba City, CA 95991
(800) 824-0214

Aqua Glass *2, 4*
PO Box 412
Adamsville, TN 38310
(800) 238-3940

Aquarius Industries *2, 3*
Route 1, Box 46D
Industrial Park
Savannah, TN 38372
(800) 223-8827

AQUATEC Health Care Products *5*
PtIP-ICM Building
1003 International Dr
Oakdale, PA 15071-9223
(412) 695-2122
See ad on page 62

Arcoa Industries *4*
2348 Meyers Ave
Escondido
CA 92029-1008
(619) 489-1170

Arjo *5, 10*
8130 Lehieg Ave
Morton Grove, IL 60053
(800) 323-1245

Ashland Manufacturing *2, 3, 4, 8*
Shepherd Care Unit
2767 Mill St
Ashland, KY 41105-0190
(606) 324-9713

ASI American Specialties *1, 9*
441 Saw Mill River Rd
Yonkers, NY 10701
(914) 476-9000

Badelift-DSI *1, 5*
16139 Runnymede St
Van Nuys, CA 91406-2913
(818) 782-6793

Bath Ease *3*
3815 Darston St
Palm Harbor, FL 34685-3119
(813) 786-2604

Bathe-Eez *4*
PO Box 365
Springfield, PA 19064
(215) 328-0802

Bathroom Gem *2*
2909 Ingersoll Ave
Des Moines IA 50312
(800) 453 8880

Bidette *7*
16816 N 35th Ave #11
Phoenix, AZ 85023
(602) 938-3990

Bobrick Washroom Equipment *1, 4*
11611 Hart St
North Hollywood, CA 91605
(818) 982-9600

Boilen Products *1, 4*
5425 Hamilton, Unit E
Cleveland, OH 44114
(216) 391-2600

Bradley *9*
PO Box 309
9101 Fountain Blvd
Menomonee Falls, WI 53051
(414) 251-6000

Brewer *1, 4, 5, 6, 7*
13901 Main St
PO Box 159
Menomenee Falls, WI 53051
(800) 558-8777

Briggs Plumbingware *3, 6, 7, 8*
4350 West Cypress
Tampa, FL 33607
(813) 878-0178

Brocar Products *9*
PO Box 68024
Cincinnati, OH 45206
(800) 827-1207

C D Sparling *1*
498 Farmer St
Plymouth, MI 48170
(313) 455-3121

Capri Plastics *10*
1801 S E Industrial Rd
PO Box 705
Brainerd, MN 56401
(800)-843-7226

Carderock *3*
PO Box 4061
Rockville, MD 20850
(202) 342-9390

Carex Health Care Products *1, 4, 7*
PO Box 20260a
Newark, NJ 07101
(800) 526-8051

Chicago Faucet *9*
2100 Clearwater Dr
Des Plaines, IL 60018
(312) 694-4400

Clark Medical Products *5, 6*
5510 Ambler Dr, Unit 10
Mississauga, Ontario
L4W 2V1, Canada
(800) 889-5295

Columbia Medical *4, 6*
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612
See ad on page 20

Columbus McKinnan *4, 5*
140 John James Audubon Pkwy
Amherst, NY 14228-1197
(716) 689-5400

Crane Plumbing/ Fiat Products *7, 8, 9*
1235 Hartrey Ave
Evanstown, IL 60202
(708) 864-9777

Cweco *1*
P.O. Box 2456
Gardena, CA 90247-0456
(310) 538-9440

DSI (Driving Systems Inc) *1, 5*
16139 Runnymede St
Van Nuys, CA 91406-2913
(818) 782-6793

Dana Douglas Medical *1, 4, 7*
PO Box 1369
Ogdensburg, NY 13669
(800) 267-3552

Danmar Products *7*
221 Jackson Industrial Dr
Ann Arbor, MI 48103
(800) 783-1998

Duralife *4, 6*
R1700 Riverside Dr
South Williamsport, PA
17701-7034
(800) 443-5433

Duro Med Industries *1, 7*
PO Box 688
Hackensack, NJ 07602
(800) 526-4753

Dynamic Life Products *4*
3701 Birch St
Newport Beach, CA 92660
(714) 756-3235

Electric Mobility *3*
#1 Mobility Plaza
Sewell, NJ 08080
(800) 662-4548

Eljer Plumbingware *1, 3, 6*
100 Forbes Ave, #850
Pittsburgh, PA 15222-1311
(412) 338-3330

ETAC USA *1, 4, 5, 6, 7*
2325 Parklawn Dr, Ste J
Waukesha, WI 53186
(800) 678-3822

Ferno Ille Div Of Ferno-Washington *10*
70 Weil Way
Wilmington, OH 45177-9371
(513) 382-1451

Fiat Products *3, 6, 8*
1235 Hartrey Ave
Evanston, IL 60202
(708) 864-9777

Franklin Brass *1*
PO Box 5226
Culver City, CA 90231
(800) 421-3375

Frohock-Stewart *1, 2, 4*
455 Whitney Ave
PO Box 330
Northboro, MA 01532-0330
(800) 343-6059

GAR Hospital Equipment *4*
PO Box 30271
Cleveland, OH 44130
(216) 546-1767

GTTI *2, 3*
1167 Hastings
Traverse City, MI 49684
(616) 941-2041

Garelick Manufacturing *4, 6, 7*
644 Second St
St Paul Park, MN 55071
(800) 457-9795

BEST COPY AVAILABLE

Manufacturers of Bathroom Access Aids

Gerber Plumbing Fixtures *6, 9*
4656 W Touhy Ave
Chicago, IL 60646
(800) 543-7237

Grand Traverse Technologies *3*
1167 Hastings St
Traverse City, MI 49686-4318
(616) 941-2041

Grant Water X *5*
986 Bedford St
PO Box 3456
Stamford, CT 06905
(800) 243-5237

Grohe America *9*
241 Covington Dr
Bloomingdale, IL 60108
(708) 582-7711

Guardian Products *1, 4, 5, 6, 7*
4175 Guardian St
Simi Valley, CA 93063
(800) 255-5022

Gunnell *4*
8440 State St
Millington, MI 48746
(800) 551-0055

Han-D-Products *1*
3999 Parkway Ln
Hilliard, O 43026-1252
(614) 876-6625

Handi-Move *4, 5*
982 Route 1
Pine Island, NY 10969
(800) 724-5305
See ad on page 37

Health and Community Living *4, 5*
9833 Whetstone Dr
Gaithersburg, MD 20879
(800) 736-6617

Homecare Products *3*
15824 SE 296th St
Kent, WA 98042
(800) 451-1903
See ad on page 32

Innovative Medical Engineering *5*
13402 S Prairie Ave
Hawthorne, CA 90250
(310) 675-8229

Innovative Products Unlimited *4, 6*
4351 W College Ave, Ste 505
Appleton, WI 54914
(800) 424-3369

International Cushioned Products *3*
#202-8360 Bridgeport Rd
Richmond, BC
V6X 3C7, Canada
(800) 882-7638

International Healthcare Products *5*
4222 S Pulaski Rd
Chicago, IL 60632
(800) 423-7886

Invacare Corporation *1, 4, 7, 9*
PO Box 4028
899 Cleveland St
Elyria, OH 44036-2125
(800) 333-6900

J. C. & Company *7, 9*
6670 30th Ave
Remus, MI 49340
(517) 967-3418

Kendall Futuro *1, 6, 7*
5405 DuPont Cir, Ste A
Milford, OH 45150
(800) 933-0210

Kohler *3, 6, 10*
444 Highland Dr
Kohler, WI 53044
(414) 457-4441

Larkotex *1, 6*
1002 Olive St
PO Box 449
Texarkana, TX 75501
(800) 972-3037

Lubidet USA *7*
950 S. Cherry St, Ste 506
Denver, CO 80222
(800) 582-4338

Lumex *1, 4, 6, 7, 9*
100 Spence St
Bay Shore, NY 11706-2290
(800) 645-5272

Maddak *1, 7*
6 Industrial Rd
Pequannock, NJ 07440
(800) 443-4926

Med/West *7*
702 South 3rd Ave
PO Box 130
Marshalltown, IA 50158
(515) 752-5446

Medi Sports Health Homecare *4*
75 York Ave
PO Box 302
Randolph, MA 02368
(800) 225-8634

MedTek Resources *1, 4*
204-A North Clay
St. Louis, MO 63122
(314) 966-0221

Moen *9*
25300 Al Moen Dr
North Almsted, OH 44070
(800) 553-6636

Medical Surgical Specialties *3*
Home Care Division
5148 Lovers Ln
Kalamazoo, MI 49002
(800) 527-5672

Nor-Am Patient Care Products *2, 10*
2410 Speers Rd
Oakville, Ontario
Canada L61 5M2
(905) 825-0094

Omni Manufacturing *1, 6*
4355 International Blvd
Norcross, GA 30093
(800) 554-9215

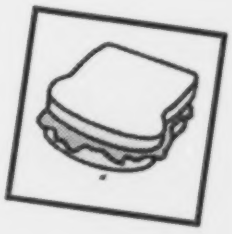
Ondine from Interbath *9*
665 N Baldwin Park Blvd
City of Industry
CA 91746-1491
(800) 423-9485

Ortho-Kinetics *4*
W220 N507 Springdale Rd
PO Box 1647
Waukesha, WI 53187-1647
(800) 824-1068

imaginart

Let us help you and your child with friendly, high quality materials:

- picture communication
- feeding and swallowing
- language development *featuring the Hanen Program*
- toys and games to train daily living skills



Pictures shown are communication stickers from our Pick 'n Stick Primary Pack.

Call or write for our free catalog:
Imaginart Communication Products
307 Arizona Street, Dept. EP4, Bisbee, AZ 85603
(800) 828-1376

Circle # 41

* Improves coordination, postural control and muscle tone.
* Provides independence.
* Secured in center with belt or seat.
* Trade-in policy.
* S.M.L
* Covered by most insurance companies.

THE WATER WALKER

* Prone or supine support.
* Contour lines that allow use of arms and legs.
* Straps to secure person on float.
* Pillow for head support.
* S.M.L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

VISA MasterCard

592

Circle # 170

Key
1. grab bars, tub rails
2. accessible showers
3. adapted bathtubs
4. seats, benches, chairs for shower; or tub transfer seats
5. bathtub lifts
6. adaptive toilets, commodes, portable commodes
7. toilet seats, supports, accessories
8. adaptive sinks
9. faucets, temperature-control faucets, fixtures, handheld showers, accessories
10. whirlpool baths, hydrotherapy devices

PCP Champion *1*
PO Box 125
Ripley, OH 45167-0125
(800) 888-0867

Panasonic *4*
One Panasonic Way
Secaucus, NJ 70940
(201) 348-7231

Parker Bath Developments *10*
Village Green Business Center
805 Teal Dr
Gallatin, TN 37066
(800) 457-8827

Porta Shower of America *2, 9*
3 Dunham Rd
Billerica, MA 01821-5728
(800) 422-0098
See ad on page 61

Porto Lift *5*
PO Box 5
Higgins Lake, MI 48627
(517) 821-6688

J.A. Preston Corporation *1, 4, 5, 7*
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
See ad on back cover

Rehab Center for Children *3, 6*
633 Wellington Cres
Winnipeg, Manitoba
R3M 0A8 Canada
(204) 452-4311

REON *9*
7486 La Jolla Blvd, #555
La Jolla, CA 92037
(800) 776-7366

Rifton Equipment *4, 7*
Rte 213, PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8799

ROHL *9*
1559 Sunland Ln
Costa Mesa, CA 92626-1514
(800) 777-9762

Rollins Healthcare *5*
7201 Haven Ave. #321
Alta Loma, CA 91701
(800) 765-7752
See ad on page 33

Safe T Bath *3*
185 Millbury Ave
Millbury, MA 01527
(508) 865-2361

SafeTek International *1, 3, 4, 9*
4340 Fortune Pl Unit A
West Melbourne, FL 32904
(800) 950-3664

Sando Handicap Aids *4, 6*
PO Box 86
Hurley, MS 39555
(800) 626-1761

Showerveil *9, 10*
P.O. Box 88
Dowagic, MI 49047
(800) 458-9036

Silcraft *2, 4, 5, 6, 10*
528 Hughes Dr
Traverse City, MI 49684
(800) 678-7100

Stern Williams *9*
PO Box 8004
Shawnee Mission, KS 66208
(913) 362-5635

Sunrise Medical *4*
2355 Crenshaw Blvd, #150
Torrance, CA 90501
(310) 328-8018

Technically Unique Bathing Systems *3*
7 Monroe St
Troy, NY 12180
(518) 274-2284

Tetra Development Society *1, 4*
Plaza of Nations, Box 27
770 Pacific Blvd, S
Vancouver, BC
V6B 5E7, Canada
(604) 688-6464

Thermal Electric *10*
455 Rte 30
Imperial, PA 15126
(800) 633-8080

TOTO KIKI USA *6, 9*
415 W Taft Ave, Unit A
Orange, CA 92665
(714) 282-8686

Tri-S-Sales and Manufacturing *4*
PO Box 623
Highway 81 South
Grafton, ND 58237
(800) 279-1400

Trujillo Industries *4, 7*
8038 Allport Ave
Santa Fe Springs, CA 90670
(310) 696-0539

Tub Master *2*
413 Virginia Dr
Orlando, FL 32803
(800) 327-1911

Tubular Fabricators *1, 4, 7*
600 West Wythe St
Petersburg, VA 23803
(800) 526-0178

Tubular Specialties Manufacturing *1, 9*
13011 South Spring St
PO Box 60262
Los Angeles, CA 90060
(800) 225-5876

Tuffcare *4*
2700 Saturn St, #A
Brea, CA 92621-6704
(800) 367-6160

Ultraflo Corporation *9*
Perkins Industrial Pk
PO Box 2294
Sandusky, OH 44870
(419) 626-8182

Universal Rundle *1, 2, 9*
PO Box 29
New Castle
PA 16101-0960
(412) 658-6631

Winco *1, 4*
5516 SW First Ln
Ocala, FL 34474-9307
(800) 237-3377

Work Stations *5*
165 Front St
Chicopee, MA 01013
(800) 759-6948

Berkshire Meadows

is a private, non-profit year-round residential school for children and adolescents who are developmentally delayed and may be multiply disabled.

We believe that everyone,no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, young people can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Functional Communication used for an advanced approach to behavior management

Associations with leading specialists and major medical centers throughout the country

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road, Housatonic,
MA 01236 (413) 528-2523

Circle # 6
593

Incontinence Resources

The HIP Resource Guide

The 1994 edition of the *Help for Incontinent People (HIP) Resource Guide* provides information on products and services for people with incontinence.

The guide was developed to assist people who are undergoing medical treatment for incontinence and for people whose incontinence cannot be cured.

The resource guide lists all companies that manufacture or distribute incontinence products and have made themselves known to HIP. The guide categorizes products, manufacturers, distributors and mail/phone-order resources. The last section of the resource guide lists organizations that may provide helpful information for people with incontinence and their families. It includes names, addresses, telephone numbers and a description of the services provided by each group.

The *Help for Incontinent People Resource Guide*, published every two years, is just one service provided by HIP, a national, nonprofit organization. HIP also publishes a quarterly newsletter and provides audio/visual programs, books, educational leaflets, a continence referral service and support and advocacy. For a free information packet, send $1.00 and a long, self-addressed, stamped envelope to HIP, P.O. Box 544, Union, SC 29379. The resource guide can be ordered by calling (800) 252-3337; $12, includes postage and handling. HIP members ($15/year) receive the resource guide free.

The Simon Foundation for Continence

The Simon Foundation for Continence is an organization dedicated to bringing the topic of incontinence out of the closet and removing its stigma. The Simon Foundation is also dedicated to education for people affected by incontinence, their families and the health care professionals who provide their medical care.

The Foundation published the first book geared toward the general public on the topic of incontinence. That book, *Managing Incontinence: A Guide to Living with Loss of Bladder Control*, may be very helpful to parents of teenagers who are incontinent. The book is available from the Foundation ($11.95, includes postage and handling).

The Simon Foundation offers a wealth of other information including books, videotapes and reprints. The Foundation also offers a quarterly newsletter for members ($15/year). For a free information packet, call (800) 237-4666 or write to the Simon Foundation for Continence, P.O. Box 835, Wilmette, IL 60091.

Manufacturers of Incontinence Products

3M Health Care *5*
270-4A-05, 3M Center
St. Paul, MN 55144-1000
(800) 364-3577

Access Medical Supply ... *2*
2006 Crown Plaza Dr
Columbus, OH 43235
(800) 242-2460
See ad on page 25

Acme United Corp *5*
75 Kings Hwy Cutoff
Fairfield, CT 06430
(800) 835-2263

KEY:

1. *disposable products* such as diapers, briefs, inserts, underpads
2. *reusable products* such as diapers, briefs, pants, panties, liners, underpads and sheets
3. *external urinary collection devices* such as catheters and accessories
4. *fecal incontinence systems*
5. *skin care products* such as special cleaners, lotions, creams
6. *deodorizing products*
7. *bedwetting products*
8. *biofeedback systems*

Allstate Medical Products *2*
3100 Ranchview Ln
Minneapolis, MN 55447
(800) 328-2915

American Health Products *1, 2, 11*
5353 Wayzata Blvd,
Ste 615
Minneapolis, MN 55416
(800) 651-6223

American Medical Systems *3*
Incontinence Info Center
PO Box 9
Minneapolis, MN 55440
(800) 843-4315

Americare Products *2*
3950-A Nebraska St
Newportville, PA 19056
(800) 220-2273

Andermac *6*
2626 Live Oak Hwy
Yuba City, CA 95991-8810
(800) 824-0214

Antiodorant® Technologies *5, 6*
8000 West 20th Ave
Hialeah, FL 33016

A-T Surgical Mfg Co .. *2, 3*
115 Clemente St
Holyoke, MA 01040
(800) 225-2023

Bard Patient Care *3, 4, 5, 6*
111 Spring St
Murray Hill, NJ 07974
(800) 526-4930

Barna Limited *3*
1680 Quincy Ave, Ste C
Naperville, IL 60540
(800) 775-2276

Baxter Clinical Alternate Site *3, 5*
One Parkway North, Ste 100
Deerfield, IL 60015
(800) 635-6121

B-Dry *2*
2555 Merrick Rd
Bellmore, NY 11710
(800) 826-2379

Beaumont Products *5, 6*
2197 Canton Rd, Ste 201
Marietta, GA 30066
(800) 451-7096

Bell-Horn *1, 2*
William H. Horn & Brothers
451 North Third St
Philadelphia, PA 19123-4197
(800) 366-4676

Biosearch Medical Products *8*
35 Industrial Pkwy
PO Box 1700
Somerville, NJ 08876-1276
(800) 326-5976

Biotechnics Mgmt Ltd *2*
2038 East 3110 South
Salt Lake City, UT 84109
(801) 484-6833

Birchwood Laboratories *5*
7900 Fuller Rd
Eden Prairie, MN 55344
(612) 937-7943, Ext 1

Boston Pacific Medical ... *3*
451 D St, Ste 811
Boston, MA 02210
(800) 735-8505

Bottom Line Diapers *2*
11240 240th St
Scandia, MN 55073
(612) 257-5292

Byram Healthcare Centers *3*
75 Holly Hill Ln
Greenwich, CT 06830
(800) 354-4054

Calgon Vestal Laboratories *5*
PO Box 147
St. Louis, MO 63166
(800) 325-8005

Camp International *2*
PO Box 89
Jackson, MI 49204
(800) 492-1088

Care-Tech Laboratories *5, 6*
3224 South Kings Hwy Blvd
St. Louis, MO 63139
(800) 325-9681

Carex Health Care Products *3*
39 Tompkins Point Rd
PO Box 20260A
Newark, NJ 07114
(201) 824-7637

Carrington Laboratories *5, 6*
2001 Walnut Hill Ln
Irving, TX 75038
(800) 358-5205

Caring Products International *1, 2*
250 Park Ave, Ste 1930
New York, NY 10177
(212) 599-2888

Cascades H.B.A. *1, 2*
First St
Palmer, MA 01069-0720
(800) 666-1205

Cascades P.S.H. *2*
999 Farrel St
Drummondville, Quebec
Canada J2C-5P6
(819) 477-5077

Changing World Products *6*
669 Summit St
Englewood Cliffs
NJ 07632
(201) 567-4227

The Clinipad Corp *5*
66 High St
Guilford, CT 06437
(800) 243-6548

Coloplast *3*
5610 West Sligh Ave
Ste 100-C
Tampa, FL 33634
(800) 237-4555

Comfort *2*
377 Bering Ave
Toronto, Ontario
Canada M8Z-3B1
(416) 763-6740

Comfort Concepts *2*
114 Essex St
Rochelle Park, NJ 07662
(800) 935-2241

Confab (ICD Industries) *1, 2*
601 Allendale Rd
King of Prussia, PA 19406
(800) 262-0042

ConvaTec *3*
A Bristol-Myers Squibb Co
PO Box 5254
Princeton, NJ 08543-5254
(800) 422-8811

Cypress Medical Products *3*
1202 South Rte 31
McHenry, IL 60050
(800) 334-3646

Dacomed *3*
1701 East 79th St
Minneapolis, MN 55425
(800) 328-1103

Dale Medical Products ... *3*
PO Box 1556
7 Cross St
Plainville, MA 02762
(800) 343-3980

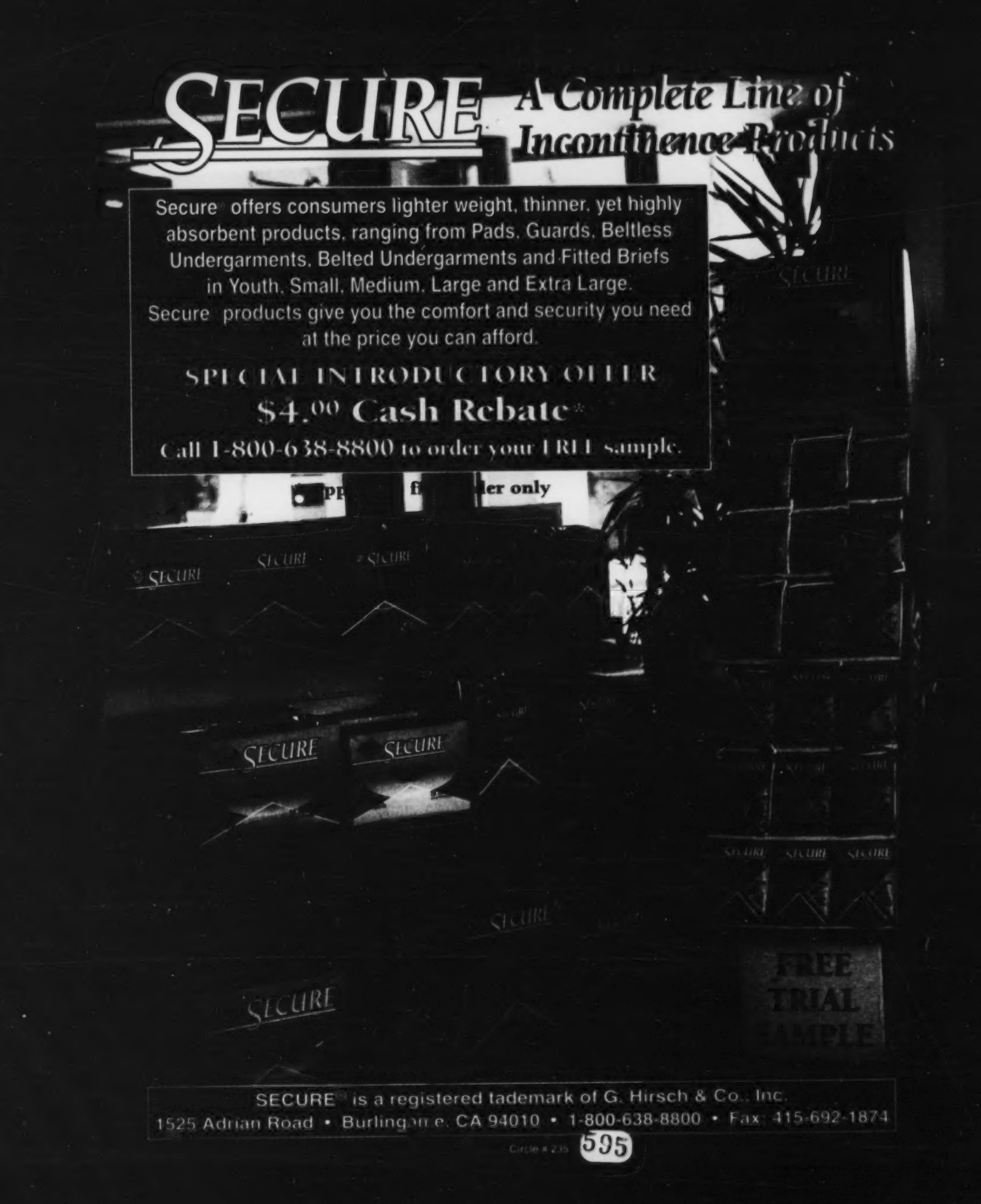
Danmar Products *2*
221 Jackson Industrial Dr
Ann Arbor, MI 48103
(800) 783-1998

Dav-Mar Medical Products *2*
35 East Grassy Sprain Rd
Yonkers, NY 10710
(800) 736-1800

DeWitt USA *6*
1604 Stockton St
Jacksonville, FL 32204
(800) 735-0666

Dow Hickam Pharmaceuticals *5*
PO Box 2006
Sugarland, TX 77487
(800) 231-3052

594


SECURE
A Complete Line of Incontinence Products
Secure® offers consumers lighter weight, thinner, yet highly absorbent products, ranging from Pads, Guards, Beltless Undergarments, Belted Undergarments and Fitted Briefs in Youth, Small, Medium, Large and Extra Large.
Secure® products give you the comfort and security you need at the price you can afford.
SPECIAL INTRODUCTORY OFFER
$4.00 Cash Rebate*
Call 1-800-638-8800 to order your FREE sample.
SECURE
FREE TRIAL SAMPLE
SECURE® is a registered tademark of G. Hirsch & Co., Inc.
1525 Adrian Road • Burlingame, CA 94010 • 1-800-638-8800 • Fax: 415-692-1874
Circle # 235
595

Incontinence Manufacturers

Dundee Mills Healthcare Products.....*2*
111 West 40th St
New York, NY 10018
(212) 840-7200

Duraline Medical Products.....*2; 3*
324 Werner St, PO Box 67
Leipsic, OH 45856
(800) 654-3376
See ad on page 57

Dura Tex.....*1, 2*
PO Box 67, Dept 315
Leipsic, OH 45856
(800) 628-4761

Duro-Med Industries...*1, 2*
301 Lodi St
Hackensack, NJ 07602
(800) 526-4753

Dynarex Corp.....*5*
One International Blvd
Brewster, NW 10509
(800) 431-2786

Edley Enterprises.....*2*
PO Box 429
Sanbornville, NH 03872-0429
(603) 473-2539

Empi.....*8*
1275 Grey Fox Rd
St. Paul, MN 55112
(800) 325-5663

EZMT Valve Co.....*3*
22260 Davenrich St
Salinas, CA 93908
(408) 484-1987

Family Clubhouse.....*2*
6 Chiles Ave
Asheville, NC 28803
(800) 876-1574
See ad on page 41

Ferno-Ille.....*5, 6*
70 Weil Wy
Wilmington, OH 45177-9371
(800) 733-3766

First Quality Products.....*2*
80 Cuttermill Rd, Ste 409
Great Neck, NY 11021
(800) 488-3130

Freestyle Medical Supplies.....*1, 2*
336 Green Rd
Stoney Creek, Ontario
Canada L8E-2B2
(905) 662-4281

KEY:

1. *disposable products* such as diapers, briefs, inserts, underpads
2. *reusable products* such as diapers, briefs, pants, panties, liners, underpads and sheets
3. *external urinary collection devices* such as catheters and accessories
4. *fecal incontinence systems*
5. *skin care products* such as special cleaners, lotions, creams
6. *deodorizing products*
7. *bedwetting products*
8. *biofeedback systems*

G. Hirsch and Company..*2*
1525 Adrian Rd
Burlingame, CA 94010
(415) 692-6980
See ad on page 51

Gabby's.....*2*
Bay 14
1420 40th Ave NE
Calgary, Alberta
Canada T2E-6L1
(403) 250-7079

General Econopak.....*2*
1725 North 6th St
Philadelphia, PA 19122
(215) 763-8200

George Disposables.....*1*
2221 Peachtree Rd, Ste D
Atlanta, GA 30309
(800) 950-3427

Geri-Care Products.....*2*
252 Wagner St
Middlesex, NJ 08846
(201) 469-7722

Greenwald Surgical Co...*3*
2688 De Kalb St
Lake Station, IN 46405
(219) 962-1604

Hallmark Industries....*5, 6*
564 Kings Hwy
West Springfield, MA 01089
(413) 739-9148

Hasty Collector Co.....*3*
5421 Oxford
Kansas City, MO 64133
(816) 358-6083

HDIS.....*2*
1215 Dielman Industrial Ct
Olivette, MO 63132
(800) 538-1036

Healthpoint Medical...*5, 6*
2400 Handley-Ederville Rd
Fort Worth, TX 76118
(800) 441-8227

Hollister.....*3, 5, 6*
2000 Hollister Dr
Libertyville, IL 60048
(800) 323-4060

Hospital Specialty Co.....*2*
7501 Carnegie Ave
Cleveland, OH 44103
(800) 228-3273

Hosposable Products..*1, 2*
PO Box 8609
Somerville, NJ 08876
(800) 221-1302

The Hoxeng Group.....*6*
120 Landing Ct, Ste J
Novato, CA 94947
(800) 395-0390

Humanicare International.....*1, 2, 6*
1200 Airport Rd
North Brunswick, NJ 08902
(800) 631-5270

Hy-Tape Surgical Products Corp.....*2*
772 McLean Ave
Yonkers, NW 10704
(800) 248-0101

Hydas.....*1, 2*
PO Box 420
Hershey, PA 17033
(800) 358-5583

Inbrand Corp.....*1*
1165 Hayes Industrial Dr
Marietta, GA 30062
(800) 241-8205

InCare Medical Products.....*8*
2000 Hollister Dr
Libertyville, IL 60048
(800) 548-3482

Incon.....*2*
509 West 9th Str
South Sioux City, NE 68776
(712) 258-4131

International Sanifem Co.....*3*
PO Box 4117
Downey, CA 90242
(310) 928-3435

J. Byrd Enterprises.....*6*
3258 Clairmont North
Atlanta, GA 30329
(404) 636-8103

J & J Engineering.....*8*
22797 Holgar Ct NE
Poulsbo, WA 98370
(206) 779-3853

Johnson & Johnson Personal Products Co.....*1*
Van Liew Ave
PO Box 900
Milltown, NJ 08850
(800) 526-3967

M.C. Johnson Co.....*3*
4292 Corporate Sq, Ste C
Naples, FL 33942-4753
(800) 553-8483

Jonas.....*7*
1113 Faun Rd
Wilmington, DE 19803-3314
(303) 478-1375

Kendall-Futuro Co.....*1*
1 Riverfront Pl, Ste 900
Newport, KY 41071
(800) 933-0210

Kimberly-Clark Corp...*1, 2*
Dept GNM-12
PO Box 2020
Neenah, WI 54957
(800) 544-1847
See ad on page 53

Kinetic Concepts.....*2*
PO Box 659508
San Antonio
TX 78265-9508
(800) 531-5346

King Ostomy Healthcare.....*6*
431 West 13th, Ste 4
Eugene, OR 97401
(503) 345-0391

Kleinert's.....*1, 2*
114 Lemonton Wy
Radnor, PA 19087
(215) 397-0788

Kloz-Ez.....*2*
1065-D Shary Circle
Concord, CA 94518
(800) 848-5540

Koregon Enterprises.....*2*
9735 SW Sunshine Ct, #100
Beaverton, OR 97005
(800) 544-4240

LL Medico USA.....*2*
1512 West Chester Pike
#255
West Chester, PA 19382
(610) 436-8831

Malik Industries.....*2*
507 School House Rd
Kennet Square, PA 19348
(610) 444-6393

Mark-Clark Products.....*2*
3601 SW 29th St, #250
Topeka, KS 66614
(913) 273-3990

Mark One Healthcare Products.....*1, 2*
100 East Ninth Ave
Runnemede, NJ 08078
(800) 631-3549

Marlen Manufacturing & Development.....*3, 6*
5150 Richmond Rd
Bedford, OH 44146
(216) 292-7060

Mason Laboratories....*3, 6*
119 Horsham Rd
PO Box 334
Horsham, PA 19044
(800) 523-2302

MB Products Ltd.....*2*
120 Swannanoa River Rd
Asheville, NC 28805
(704) 253-8874

Medi.....*3*
75 York Ave
Randolph, MA 02368
(800) 225-8634

Medical Devices International.....*3*
3849 Swanson Ct
Gurnee, IL 60031-1225
(800) 323-9035

Medline Industries.....*2, 5*
One Medline Pl
Mundelein, IL 60060
(800) 323-5886

Medpro.....*2*
1985 Rutgers University Blvd
Lakewood, NJ 08701
(800) 257-5145

Mentor Urology.....*3, 6*
5425 Hollister Ave
Santa Barbara, CA 93111
(800) 328-3863

Microban Products.....*2, 5*
11515 Vanstory Dr, Ste 110
Huntersville, NC 28078
(704) 875-0806

MMG Health Care.....*3*
5335 Dividend Dr
Decatur, GA 30035
(800) 334-4475

Nantucket Industries.....*2*
105 Madison Ave
New York, NY 10016
(800) 562-3774

Nature Plus.....*6*
52 Lakeview Ave, Ste 20
New Canaan, CT 06840
(203) 972-1100

Neotech Products.....*3*
9135 Alabama Ave #F
Chatsworth, CA 91311
(800) 966-0500

NeuroDyne Medical.....*8*
51 Winchester St
Newton, MA 02161-1704
(800) 328-4266

Nilodor.....*6*
PO Box 660
Bolivar, OH 44612
(800) 443-4321

Nytone Medical Products.....*7*
2424 South 900 West
Salt Lake City, UT 84119
(801) 973-4090

Out! International.....*6*
PO Box 227215
Dallas, TX 75222-7215
(800) 527-9919, Ext 0157

Palco Laboratories.....*7*
8030 Soquel Ave
Santa Cruz, CA 95062
(800) 346-4488

Palisades Pharmaceuticals.....*6*
64 North Summit St
Tenafly, NF 07670
(800) 237-9083

Paper-Pak Products....*1, 2*
1941 White Ave
PO Box 1060
La Verne, CA 91750
(714) 392-1200

Patient Care.....*1, 2, 3, 4, 5, 6, 8*
111 Spring St
Murray Hill, NJ 07974
(800) 526-4930

Perfect Fit Industries.....*2*
201 Cuthbertson St
Monroe, NC 28110
(800) 438-1516

J.T. Posey.....*3*
5635 Peck Road
Arcadia, CA 91006-0020
(800) 447-6739

Principle Business Enterprises.....*1, 2*
Pine Lake Industrial Park
Dunbridge, OH 43414
(800) 467-3224

Priva.....*2*
PO Box 448
Champlain
NY 12919-0448
(800) 361-4964

Proctor and Gamble....*1, 2*
PO Box 599
Cincinnati, OH 45201
(800) 543-0480

Professional Disposables.....*5*
Two Nice Pak Park
Orangeburg, NW 10962
(800) 999-6423

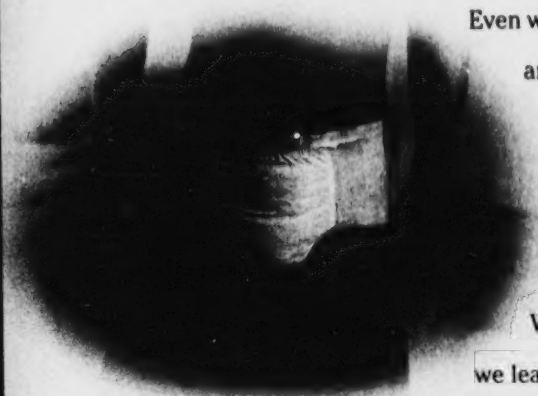
Professional Medical Products.....*2*
PO Box 3288
Greenwood, SC 29649
(800) 845-4571

Provon.....*5*
PO Box 991
Akron, OH 44309
(800) 321-9647, Ext 606

596

"Bedwetting is something I'll outgrow, but until then, I'll wear GOODNITES.™"

Introducing new PULL-UPS® GOODNITES™ Absorbent Underpants for older children—45 pounds and up. Your child slips them on at bedtime and—accident or not—wakes up to dry sheets, dry pajamas. And a whole new positive attitude.



Even with the super-absorbent lining, GOODNITES™ Absorbent Underpants are so trim, they disappear under pajamas. Nobody needs to know your child is wearing them. And with no sheets to wash, mornings are hassle free. Everyone starts the day right.

We developed GOODNITES™ with the help of pediatricians and other childhood experts. We've put all we learned about bedwetting in a book. For your free copy, send $1.00 postage and handling to GOODNITES™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

597
Circle # 147

Incontinence Manufacturers

Quality Care Incontinence Products....5
P.O. Box 162
Woodstock, MD 21163
(800) 494-4964
See ad on page 61

Restful Knights.....2
1810 Industrial Wy
P.O. Box 423
Wayne, NE 68787
(800) 322-1123

Rochester Medical.....3
1500 NW 2nd Ave
Stewartville, MN 55976
(800) 243-3315

KEY:

1. *disposable products* such as diapers, briefs, inserts, underpads
2. *reusable products* such as diapers, briefs, pants, panties, liners, underpads and sheets
3. *external urinary collection devices* such as catheters and accessories
4. *fecal incontinence systems*
5. *skin care products* such as special cleaners, lotions, creams
6. *deodorizing products*
7. *bedwetting products*
8. *biofeedback systems*

Rystan Co.....6
47 Center Ave
Little Falls, NJ 07424
(800) 553-5214

Sage Laboratories.....5
5408 Interstate Dr
Shreveport, LA 71109
(800) 960-0599

Salk Co
PO Box 452.....1, 2
119 Breaintree St
Boston, MA 02134
(800) 343-4497

Scott Health Care.....1, 2
Scott Plaza
Philadelphia, PA 19113
(800) 992-9939

Self Regulation Systems.....8
14770 NE 95th St
Redmond, WA 98052
(800) 345-5642

Sherwood.....3
1915 Olive St
St. Louis, MO 63103
(800) 428-4400

Sierra Laboratories.....3
3520 South Cambell
Tuscon, AZ 85713
(800) 726-2904

Smith & Nephew United.....3, 5, 6
11775 Starkey Rd
P.O. Box 1970
Largo, FL 34649-1970
(800) 876-1261

Special Clothes.....2
PO Box 4220
Alexandria, VA 22303
(703) 683-7343

Spenco Medical Corp.....2
PO Box 2501
Waco, TX 76702
(800) 877-3626

Stanford Professional Products.....1, 2, 5
1416 Union Ave
Pennsauken, NJ 08110
(800) 345-3929

Stearns Technical Textiles.....1, 2
100 Williams St
Cincinnati, OH 45215
(800) 426-8712

Strong Skin Savvy.....5
1 Lakeside Dr
New Providence, PA 17560
(800) 724-3952

Summit Industries.....5
PO Box 7329
Marietta, GA 30065
(800) 241-6996

Sween Corp.....5, 6
1940 Commerce Dr
PO Box 8300
N. Mankato, MN 56002
(800) 533-0464

Techno Marketing Inc.....2
307 Bacon Rd
Rougemont, NC 27572
(919) 447-1387

Thought Technology
2180 Belgrave Ave.....8
Montreal, Quebec
Canada H4A-2L8
(514) 489-8255

TMI.....2
307 Bacon road
Rougemont, NC 27572
(800) 550-4666

Tranquility Products.....1
Pine Lake Industrial
Park, Dunbridge, OH 43414
(800) 467-3224

Travis International.....7
100 Main Sumner
Coos Bay, OR 97420
(800) 437-9233

Uncommon Conglomerates.....6
287 East 6th St, Ste 610
St. Paul, MN 55101
(800) 323-4545

Undercare.....1, 2
PO Box 486
Bridgeport, CT 06604
(203) 334-4560

UniPatch.....3, 5, 6
1313 West Grant Blvd
PO Box 271
Waasha, MN 55981
(800) 328-9454

Urinette.....3
7012 Pine Forest Rd
Pensacola, FL 32526
(800) 853-3777

Urocare Products....3, 5, 6
2735 Melbourne Ave
Pomona, CA 91767-1931
(800) 423-4441

Vinyl Incontinent Products.....2
PO Box 63
Three Oaks, MI 49128
(616) 756-7382

Viro Research International.....5
178 Bodo Dr, Unit C
Durango, CO 81301
(800) 395-9929

Viscot Industries.....3
PO Box 351
East Hanover, NJ 07936
(800) 221-0658

VPI.....3
127 South Main St
PO Box 266
Spencer, IN 47460
(800) 843-4851

Whitestone Products..1, 2
40 Turner Pl
Piscataway, NJ 08854
(800) 800-2042

X-O.....6
8330 Moberly Ln
Dallas, TX 75227
(800) 442-9696

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

Ask about our complete catalog including GoodNites, Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

5 Models Available Now

BIGFOOT

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Bigfoot 4 X 4 Inc. St. Louis, MO

Circle # 42

Networking

Information from The National Parent Network on Disabilities

Parents Help Set The National Agenda

On July 10–12 a conference in Washington, DC introduced the *National Agenda for Achieving Better Results for Children and Youth with Disabilities.* The National Parent Network on Disabilities (NPND) participated in this conference with a team of five Parent Training and Information Center leaders.

The *National Agenda* includes a mission to guide future program planning for children and youth with disabilities:

All children and youth will have the right and responsibility to participate as members of the global community. In concert with the GOALS 2000: EDUCATE AMERICA ACT and the INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA), it is our mission and in the national interest, for all children and youth, including those with disabilities, to be educated to their fullest potential. Further, all children and youth will have the opportunity and necessary supports to become caring, productive, socially involved citizens who are committed to life-long learning.

NPND Annual Meeting

October 1–3, 1994
Washington, DC
- **Legislation**
- **Legislators**
- **Administration Officials**

Mark your calendars now!

Board Meeting September 30, 1994
Location: The St. James Hotel, Washington, D.C.
Reception: Sunday Evening, October 2

The National Agenda reflects the belief that a more effective educational system can be created by the year 2000 through a commitment to the values and principles embodied in its mission statement. By achieving the goals set by IDEA, every child can be assured of the best possible educational opportunities. The achievement of these goals requires a commitment to honoring these rights of children and youth with disabilities:

- Access to appropriate options designed to meet their individual needs;
- Preparation for inclusion in an integrated society; and
- Optimal and appropriate opportunities to be educated with peers who represent diverse cultures, languages and abilities.

The *National Agenda* describes a vision for the year 2000. The vision begins with images of children and youth with disabilities having access to services that will lead to self-actualization, self-determination and independence. The *National Agenda* envisions these children as highly motivated learners with individual identities, a strong sense of values and access to supports necessary to ensure a high quality of life.

Hiram Zayas, a well-known advocate for children and adults with disabilities, opened the NATIONAL AGENDA meeting in Washington, DC. Zayas, speaking as a parent and a person with a disability, provided a consumer-oriented perspective on better results for children and youth with disabilities. He focused on the importance of appropriate role models and proper preparation for the world of work.

This vision is fully compatible with national education goals and the intent of the *Goals 2000: Educate America Act.* The *National Agenda* also describes the following program components that must be in place to ensure success for children with disabilities:

- Enriched and broadened appreciation of diversity;
- School-community collaboration;
- Appropriate personnel;
- Specific accountability for better results for children and youth; and
- Appropriate technology.

For further information or to receive a copy of the *National Agenda,* contact your state director of special education or call NPND, (703) 684-6763.

Positive SSI Stories

NPND is seeking stories from families of children with disabilities about positive impacts of the SSI benefit program.

Recently, the success of national outreach programs, like the one NPND operated between 1990 and 1992, has been turned upside down. Critics of the SSI program are now complaining in the press and on television that SSI is out of control. Beginning in 1990, after the supreme court's decision in Sullivan v. Zebley made SSI medical-eligibility requirements less restrictive, a number of children with disabilities began receiving SSI for the first time. Skeptics contend that this number is far too high to accurately represent the number of truly eligible children. They have charged that families coach children to act as if they have disabilities and that families abuse the funds that they receive on behalf of their children.

Allowing these types of criticisms to stand unchallenged will seriously jeopardize the continued ability of of children with disabilities to participate in the SSI benefits program. We urgently need to collect as many positive stories as possible about the impact of the SSI program on families of children with disabilities.

Please send your story to Patricia McGill Smith, Executive Director, National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, VA 22314. For more information, call (703) 684-6763.

599

Parent Case Management for People of Color

Members of ethnic minority groups are less likely to receive community services and supports for individuals with disabilities and their families. To assist in addressing this issue, the University of Minnesota's Institute on Community Integration (ICI) is developing a program called Parent Case Management for People of Color.

This program is a collaborative effort between the Institute's Research and Training Center on Residential Services and Community Living, Arc of Hennepin County and leaders in the African-American and Native-American communities. The program's goal is to develop information, procedures and materials that can be easily used by existing community organizations. The program hopes to provide these existing community organizations with resources for parents or guardians of individuals of color who have developmental disabilities. These resources can be used to encourage these adults to take leadership roles in the management of services that they or their children receive.

The fundamental premise of parent case management is the idea that individuals with disabilities and their families can effectively handle the choices and decisions involved in their case management. Through training and technical assistance, the program gives participants the background information and skills needed to take the lead when identifying, selecting and managing the services and supports they receive. Participants develop knowledge in case management, rights, quality indicators, state-of-the-art service delivery, effective use of resources, maintenance of appropriate records and inclusion. Parent Case Management for People of Color adapts the training, materials and assistance of the Parent Coordination Project to create an effective, culturally-sensitive tool to empower individuals with disabilities, leaders and families within these communities.

Parent Case Management for People of Color is focusing first-year efforts on collaboration and networking with communities of color in selected areas of Minnesota. Next year the program will develop training and technical assistance projects, including a newsletter, in the African-American community. Third-year plans call for the extension of these services into the Native-American community. By the fifth year of the program, facilitator training and technical assistance will be in place in each of these communities.

The National Parent Network on Disabilities will collaborate with Parent Case Management for People of Color by distributing information about the materials developed by this program.

For further information contact Marijo McBride, University of Minnesota, Institute on Community Integration, 103 Pattee Hall, 150 Pillsbury Drive, Minneapolis, MN 55455, (612) 624-6830.

Leadership Changes Around the Network

This year seems to be one that will be characterized by changes in Parent Training and Information Center leadership. ***Deidre Hayden*** has resigned as executive director of the Parent

Deidre Hayden, Cherie Takemoto and Nola Flynn at the Parent Educational Advocacy Training Center in Fairfax, Virginia.

Educational Advocacy Training Center (PEATC) in Virginia. She will be replaced by ***Cherie Takemoto***. ***Joan Kilburn*** is retiring from MATRIX in California and will be replaced by ***Deidre Hayden***. Does this mean the creation of PEATC west and MATRIX east?

In other leadership changes, ***Carla Lee-Lawson*** will be leaving Iowa Pilot Parents later this summer to hang her hat at the Iowa Federation of Families for Children's Mental Health.

Joan Kilburn

We congratulate Cherie Takemoto on her new leadership position. The parent movement will remain strong if all of our new generation of leaders bring Cherie's level of commitment and skill to the job. Likewise we know that Deidre Hayden will bring her immense skills and energy to MATRIX to carry on in the tradition of excellence that Joan Kilburn has established there.

If you know of any other leadership changes, please let us know, and we'll share them here.

The National Parent Network on Disabilities Board of Directors

Richard Burden
IN*SOURCE, South Bend, IN

Joanne Butts
Washington PAVE, Tacoma, WA, *Vice President*

Amparo Crespo DeCastro
Asociacion de Padres Por Bienestar de Niños, Impedidos de PR, Inc., Rio Piedras, PR

Connie Curtin
Vermont Parent Information Center, Winooski, VT

Diana Cuthbertson
Statewide Parent Advocacy Network (SPAN), Westfield, NJ, *President*

Kathryn Erickson
Pathfinder Services of North Dakota, Minot, ND

Joe Garcia
Touchstones, Seattle, WA

Paula Goldberg
PACER Center, Minneapolis, MN

Sweet Alice Harris
Parents of Watts, Los Angeles CA

Connie Hawkins
Exceptional Children's Assistance Center (ECAC), Davidson, NC, *Past President*

Bonnie Johnson
Arkansas Parent Support and Information Network, Little Rock, AR

Joan Kilburn
MATRIX, A Parent Network & Resource Center, San Rafael, CA, *Treasurer*

Sue Pratt
CAUSE, Lansing, MI, *Vice President*

Pam Steneberg
Disability Rights Education & Defense Fund, Berkeley, CA, *Secretary*

Janet Vohs
Federation for Children with Special Needs, Boston, MA

Patricia Smith
Executive Director

600

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Insurance Coverage for Incontinence Products

Q My child has a disability and is incontinent. He will never be potty-trained. Is there any way to get our insurance company to cover the cost of his diapers?

K.D., Texas

A This is a problem for many parents of children with disabilities. Diapers are expensive, particularly when required on a long-term basis. And if they are being used as part of a doctor-recommended treatment program, logic suggests that unless they are specifically excluded by your insurance policy, they probably should be covered.

A number of issues may be related to your insurance company's decision on coverage, however. First, there is no clear set of national standards regarding items that insurance policies should cover. One of the goals of President Clinton's health care reform proposal is to establish such standards. Hopefully, this will occur in the not-too-distant future. In the meantime, an insurance company may exclude coverage for specific items as long as it does not violate contractual obligations (its agreement with the policy-holder) or state or federal regulations.

Second, insurance companies seem particularly reluctant to pay for items that are not considered a part of traditional medical care, or that may be used in a non-medical situation. One can certainly understand an insurance company's concern about establishing a precedent by covering such items. However, companies may pay for these items if it can be shown that they are part of a treatment plan for a specific medical condition that the policy covers.

Generally, insurance companies do not pay for items unless they are included on the company's list of "medically necessary expenses" and have been assigned a specific procedure code. Therefore, you must first determine whether your insurance company includes diapers on its list of "medically necessary expenses" in regard to disabilities. If diapers are not on the list, the solution needs to begin at that point.

Since this issue affects large numbers of parents, and since groups are often more effective than individual consumers, it may be useful to enlist the help of a local parent support group and a local medical organization that includes doctors specializing in the treatment of children with disabilities (your child's doctor may be able to give you the names of such organizations).

The parent support group can ask the medical association to write a letter to the insurance company confirming that the use of diapers is part of a medical treatment plan in the case of specific disabilities. In addition, the medical association may consider working with the insurance company to develop appropriate rules and procedure codes for such situations.

If diapers are already on the list of "medically necessary expenses," however, your problem is to determine why the insurance company won't pay the claims you have sent in. The problem may involve technicalities. For example, the company may pay for disposable diapers only, rather than cloth diapers, or it may require a doctor's letter explaining how the diapers are related to the treatment of a specific medical condition. A call to a supervisor at the insurance company should provide this kind of information.

Let me know what happens. Your experiences in dealing with this issue may be very helpful to other parents.

NOTE: When children are eligible for Medicaid, incontinence products may be covered. In the September issue of EXCEPTIONAL PARENT, I will discuss the Medicaid program.

Don't You Have Enough To Worry About...

Without Worrying About Incontinent Supplies?

DMP®

DURALINE® MEDICAL PRODUCTS

- For all of your bladder and bowel control needs - diapers, briefs, liners, underpads, catheters and more.
- Fast direct-to-your-door delivery.

Call Today For A FREE Catalog!

Circle #20

1-800-654-3376

DURALINE MEDICAL PRODUCTS

324 Werner St. • P.O. Box 67 • Leipsic, OH 45856

Circle # 20

000 601

Crystal Springs School

A PROGRAM OF THE
INSTITUTE FOR DEVELOPMENTAL DISABILTIES, INC.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availability.
- Licensed by the Massachusetts Office for Children.
- Approved by the Massachusetts Department of Education.
- Member of the Massachusetts Association of Approved Private Schools.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537
Circle #151

Circle # 151

Attends Insert Pads

Attends Underpads

ARC
Home Health Products
RR#4 Box 161 • Oneonta, New York 13820

Attends Undergarments

If you use or would like to try

ATTENDS® Brand
Quality Incontinent Care Products

CALL US!

Your Satisfaction is our Concern!

- UPS deliveries right to your door
- No add-on shipping & handling charges
- Personal, knowledgable service
- Visa/Mastercard accepted

SAVE!

SAVE! BUY BULK

Check our pricing - You will save!

Inquiries and/or to place an order

1-800-278-8595
Monday-Friday
8:00am-5:00pm EST

Attends Disposable Washcloths

Ultra Attends Brief

Circle # 229

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent*.

Directory of Advertisers

Circle	Advertiser	Page
244	AACPDM	62
9	AccessAble Environments	12
228	Access Medical Supply	25
3	Adaptive Design Shop	14
234	American Standard	5
128	Aquatec Health	62
170	Aquatic Therapy	48
229	ARC/Otsego	58
2	ATT	C2
167	Ballard Medical Products	22
6	Berkshire Meadows	49
7	BHC-JA Preston	C4
185	Childrens's Specialized Hospital	25
90	Chrysler	31
227	Clinician's View	65
186	Civitan International	44
13	Columbia Medical	20
11	Columbia Medical	40
151	Crystal Springs School	58
18	Cumberland Hospital	35
19	Devereux	17
230	Direct Delivery	6
20	Duraline Medical Products	57
25	Equipment Shop	44
26	Estate Planning	41
27	Evergreen Center	37
174	Family Clubhouse	41
233	Fishbourne International	29
30	Ford	7
235	G. Hirsch & Co	51
199	Hacienda de Los Angeles	41
35	Handi-Move	37
36	Haverich Ortho-Sport, Inc	12
38	Heartspring	16
39	HMS School	42
40	Homecare	32
41	Imaginart	48
42	Innovative Products	54
200	Interior Planning and Design	62
211	InvoTek	14
44	Jay Medical	3
147	Kimberly Clark	53
236	Mentor Corporation	C3
56	Nu-Tech Health Products	14
219	Oralgiene	19
103	Rhamdec	11
232	Rock N' Roll	14
67	Rollins Healthcare	33
68	Sentient Systems	42
75	St. John's Villa	37
202	Temasek Telephone	33
122	TMI	13
237	Woodbury Products	44
86	Woodbury Products	54

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106.

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1 ❑ Less than $30,000
2 ❑ $30,001 - $40,000
3 ❑ $40,001 - $50,000
4 ❑ $50,001 - $75,000
5 ❑ $75,001 - $100,000
6 ❑ $100,000+

C. Do you live in a(n):

7 ❑ Home 8 ❑ Own 9 ❑ Rent
10 ❑ Apartment 11 ❑ Own 12 ❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13 ❑ One 14 ❑ Two 15 ❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16 ❑ one month
17 ❑ three months
18 ❑ nine months
19 ❑ one year

Issue Date: August 31, 1994

Expiration Date: November 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1 ❑ Less than $30,000
2 ❑ $30,001 - $40,000
3 ❑ $40,001 - $50,000
4 ❑ $50,001 - $75,000
5 ❑ $75,001 - $100,000
6 ❑ $100,000+

C. Do you live in a(n):

7 ❑ Home 8 ❑ Own 9 ❑ Rent
10 ❑ Apartment 11 ❑ Own 12 ❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13 ❑ One 14 ❑ Two 15 ❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16 ❑ one month
17 ❑ three months
18 ❑ nine months
19 ❑ one year

Issue Date: August 31, 1994

Expiration Date: November 30, 1994

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA
POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 5446
PITTSFIELD MA 01203-9321

60

Market Place

Bibs

Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No online charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Clothing

Adrian's Closet
P.O. Box 9506
Rancho Sante Fe, CA 92067
(800) 831-2577
Free catalog of fun-to-wear adaptive clothing available now.

Conferences

Assistive Technology Expo '94
Wednesday, September 21, 1994
10:30 am – 7 pm
Westchester County Center
White Plains, NY
Hudson Valley's largest show of assistive technology for individuals with disabilities. Full day of exhibits, demonstrations and workshops of products and services for individuals with disabilities, their families, elders, service providers, educators, and employers. Sponsored by: Westchester Institute for Human Development/UAP, Westchester County Medical Center, & the NYS Office of Advocate for the Disables, NYS TRAID Project. For more information call 914-285-7364

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical Save $$$ on all school needs—position/seating equip., Roho/Jay cushions, standers. Call 800-877-9100 for free brochure.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Dowd Medical
1010 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been serving the area since 1930. For personal service and quality equipment call Dowd.

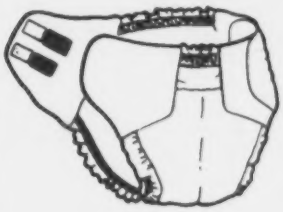
Free Catalogs

Consumer Care Products, Inc.
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.



Quality Care Incontinence Products
P.O. Box 162
Woodstock, MD 21163
1-800-494-4984
YOUTH PRODUCT SPECIALIST
Reusable diapers, "doublers", training/overnight pants, wipes; *flushable* liners; waterproof bags, bed/chair pads; skin care; adaptive toothbrushes. DISTRIBUTORS NEEDED WORLDWIDE! Call (410) 521-5871 outside USA.

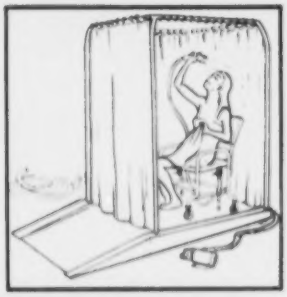
children & adult sizes

Taga, Inc.
PO Box 313
Somerset, NJ 08873
Choose from a variety of Reusable pants and disposable liners/briefs for children and adults. Write for FREE Catalog!

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Showers



Porta Shower of America
3 Dunham Rd
Billerica, MA 01821
(800) 422-0098; fax: (508) 663-6709
This shower:
• has a free-standing design • sets up in minutes • has lightweight components • is easy to maintain • is accessible from 4 sides • can be used in any room • stores easily • needs no tools • comes complete (no plumbing needed)

Books, Audio/Video & Educational Material

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Publications

Hydrocephalus News/Notes
Published quarterly for affected individuals/ families & professionals who specialize in their care. Highlights: medical/technical articles, human interest stories, great resources! A. Liakos, Editor, HNN, 1670 Green Oak Circle, Lawrenceville, GA 30243. $25 year.

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry.

INTERIOR PLANNING & DESIGN, INC.

Custom designed to your needs:
Institutional, Home,
Office,
Health Care.

Turnkey operation, including furniture,
U.S.A. and International.

2 Annabelle Lane
Florham Park, NJ 07932
(201) 966-0220
Fax (201) 966-6894

Circle # 200

We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

West Virginia

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

Accessing the World for People with Disabilities
AACPDM
american academy for cerebral palsy and developmental medicine
48th Annual Meeting
New Orleans
Sept. 29 - Oct. 1, 1994

AACPDM
American Academy for Cerebral Palsy and Developmental Medicine
6300 North River Road, Suite 727
Rosemont, Illinois 60018-4226
Phone 708-698-1645 Fax 708-823-0536

Circle # 244

MAKE BATHTIME WITH YOUR CHILD A PLEASURE NOT A CHORE . . .
With an Aquatec Bathlift

- Model & accessories to accommodate various disabilities
- Head & back supports for controlled body positioning
- Safe, non-slip transfer surface
- Portable and simple to install

For more information on our unique and affordable bathlifts call, write or fax:

AQUATEC® The Bathlift Specialists
Health Care Products, L.P.
PIIP-ICM Building • 1003 International Drive
Oakdale, PA 15071-9223
Phone: 412-695-2122 • Fax: 412-695-2922

Circle # 128

606

WHAT'S HAPPENING

Let's Eat is a new video that provides practical information on feeding a child who is visually impaired, and on helping the child to develop independent eating skills. The video, which costs $15.00, explains the stages a child goes through in learning to eat. The video features parents with children of various ages. It also discusses common feeding problems of children with visual impairments and possible solutions to these difficulties. A 28-page booklet, also called *Let's Eat*, is available in English or Spanish and is free to parents of children with visual impairments ($3.00 for others).

Both video and booklet are available from the Blind Children's Center, 4120 Marathon St., Los Angeles, CA 90029, (800) 222-3567 (CA only), (800) 222-3566 (US). (Add 20% of total order for shipping and handling.)

The Blind Children's Center offers a number of other booklets and videos covering topics such as play, language development, motor skills and family coping. All booklets are free to parents of children with visual impairments ($1.50–3.00 for others). Contact the Center for more information.

National Leadership Conference

A National Leadership Conference, sponsored by the Epilepsy Foundation of America, will be held September 29–October 2, 1994 in Alexandria, Virginia. The conference will be a comprehensive training opportunity for professionals, volunteers and families coping with seizures and other disabilities. Topics to be covered include legislation, learning disorders, seizure medications, advocacy and education. For more information, contact Sandra Price, Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785, (301) 459-3700.

Support Groups

• ***Moebius syndrome*** is caused by absent or decreased sixth and seventh cranial nerve development, and results in facial paralysis. The Moebius Syndrome Foundation, an information and communication network, was recently formed by parents of children with this condition. Moebius Syndrome Foundation, P.O. Box 993, Larchmont, New York 10538, (914) 834-6008.

• A new support group is available to families of children with ***Lesch-Nyhan disease*** (LND). LND is a genetic disorder that affects only males. Individuals with LND have mental retardation and, in most cases, engage in self-mutilation. International Lesch-Nyhan Disease Association, c/o Leslie Cornely, 11042 Ferndale St., Philadelphia, PA 19116, (215) 677-4206.

• The ***TEF-VATER*** Support Network is a group dedicated to the support of children and adults born with tracheoesophageal fistula, esophageal atresia or VATER association (vertebral anomalies, imperforate anus, tracheoesophageal anomalies, renal anomalies and/or radial dysplasia). Services include family matching, referral, a quarterly newsletter and a directory of members. Contact Terri Burke, 15301 Grey Fox Rd., Upper Marlboro, MD 20772, (301) 952-6837.

• Prevent Blindness in Premature Babies (PBPB) is a group that provides support and information to parents of children who have ***retinopathy of prematurity*** (ROP). ROP is a retinal disease that prevents proper development of the eye and can lead to permanent damage and blindness. Contact Margaret Watson, P.O. Box 44792, Madison, WI 53744-4792, (608) 845-6500. A free copy of PBPB's newsletter is available (specify print or Braille); tax-deductible donations are much needed and gratefully accepted.

• ***Mucolipidosis Type IV*** (ML4) is a neurometabolic genetic disorder that primarily affects people of Askenazi Jewish descent. Experts believe that many cases go undiagnosed or misdiagnosed as "cerebral palsy" or "pervasive developmental delay of unknown etiology." Families who have one child with ML4 have a 25 percent chance of having another affected child; non-affected siblings may be carriers. Accurate diagnosis of ML4 requires analysis of skin or conjunctival biopsies with an electron microscope.

Early symptoms of ML4 may include strabismus (crossed eyes), visual problems, excessive drooling, impaired speech, variable degrees of corneal clouding and delay in reaching major motor milestones such as sitting, crawling or walking.

For more information, contact the ML4 Foundation, 6 Concord Dr., Monsey, NY 10952, (914) 425-0639 or (718) 434-5067.

Publications

• The University of Kansas offers a 40-page booklet entitled *What You Need To Know About Your Child With An Emotional Disability and the Individualized Educational Plan*. The booklet, which costs $3.00, is intended to give parents the information they need to be effective advocates for an education that will meet their children's unique needs. Some information in this booklet applies specifically to the state of Kansas; much is applicable anywhere. Available from John Poertner, School of Social Welfare, Twente Hall, University of Kansas, Lawrence, KS 66045-2510, (913) 864-4720. Make checks payable to "School of Social Welfare."

• The National Down Syndrome Society has introduced a new magazine designed to educate teenagers and young adults about people with Down syndrome who are included with them in the community, at school, on the job and in social and recreational activities. The premier issue of *News 'n Views* includes articles written by a number of teens and young adults with Down syndrome. Editor-in-chief Chris Burke is well-known for his role as "Corky" on the long-running television show *Life Goes On*. Subscriptions to *News 'n Views* are free; contact National Down Syndrome Society, 666 Broadway, New York, NY 10012, (800) 221-4602.

607

NEW PRODUCTS

ZOOMCAPS

These large-print, adhesive computer key labels are designed to assist individuals with low vision; they may also be useful for children who are learning to type. Labels are printed in 40-point type and include alphanumeric characters and other special keyboard keys. ZoomCaps labels are available with white characters on a black background or black characters on an ivory background to suit individual preferences and needs. The 91-label sets are available for IBM and IBM-compatibles, Apple IIe and IIc, and Macintosh keyboards.

Meeting the Challenge, Colorado Springs, CO 80907

Circle # 238

PROTECTACAP® PROTECTIVE HEADGEAR

ProtectaCap is lightweight, custom-fitting protective headgear that was specifically designed for little noggins! Now available in newborn through adult sizes, these caps may be ideal for post-surgery, therapeutic activities and for individuals requiring head protection. The caps are made of shock-absorbent Ensolite® foam and have a Velcro® closure. They provide maximum head coverage along with maximum hearing, ventilation and comfort. ProtectaCap comes in a variety of colors and is machine-washable and -dryable!

Plum Enterprises, Worcester, PA 19490

Circle # 239

ABOVO™ PERSONAL COMMUNICATING DEVICE

One finger is all it takes to communicate! The Abovo Personal Communicating Device (PCD) has a unique keyboard with 41 large keys and a built-in keyguard. Its 40-character, super-twist liquid crystal display can be read from any angle. An optional Remote Display Unit can be read by individuals up to 20 feet away! This unit also can be used with Apple and IBM computers—text can be downloaded to a computer for use with word processing software.

Abovo, Springfield, MA 01129

Circle # 240

CROSSSCANNER

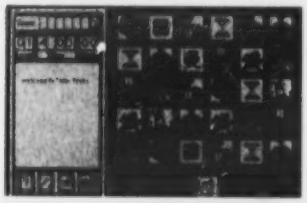
This program is designed to allow a person using a single switch or any pointing device to run software for Macintosh and Windows (IBM and compatibles) applications. The single switch is connected through a switch-adapted trackball. Single-switch mouse moves and clicks, double clicks, drags and use of menu bars are performed by direct cross-scanning. This software can be fine-tuned to the needs of the user. Text can be entered via an on-screen keyboard.

R.J. Cooper & Associates, Dana Point, CA 92629

Circle # 241

TREKS LASERDISC COMPANION SERIES

Earth Treks,™ Ecology Treks,™ and Time Treks™ are all included in this series of cross-curricular discovery software that utilizes encyclopedic reference materials and an exciting computer game to make learning unforgettable. These interactive programs cover geography, ecology and history with Bit-Bot, the knowledge robot. Visual and graphic reinforcement of academic subjects may help some children with learning disabilities; it can help all children to maintain interest in their lessons! The TREKS Laserdisc Companion series is available for Macintosh computers.



Magic Quest, Palo Alto, CA 94301

Circle # 242

HELMET HELPERS

Bows, bi-colors, prints, hearts, splatter designs and 10 assorted colors mean an almost unlimited number of ways to make protective helmets for kids more attractive and fun to wear. These Lycra® covers fit over Danmar's protective helmets and come with a "hard visor" and optional decorative bow!

Danmar Products, Ann Arbor, MI 48103

Circle # 243

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

608

Clinician's View

Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices.The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays,

by Susanne R. Hays, M.S.,R.N.,C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. **ED 077OD**

Effective Intervention For Self-Feeding Success,

by Christine A. Nelson, Ph.D.,OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. **ED 078OD**

Massage For The Infant With Developmental Disabilities,

by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant's individual concerns. A valued resource for every parent to assist their child's development.

ED 079DD

Near Normal Feeding For Infants With Oral-Facial Anomalies,

by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant's born with cleft lip and/or palate can be very difficult.Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies that parents can follow. **ED 080OD**

Mail to: **Exceptional Parent,** Dept. EP9408, P.O. Box 8 045, Brick, N.J. 08723
Or call **1-(800)-535-1910**

QTY	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. - $3.50 for 1 item, 75¢ for each additional item. Foreign - $6.50 for 1 item, 75¢ for each additional item.

Sub-Total	
N.J. Res. 6% tax	
Shipping	
TOTAL	

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: Visa Mastercard

Account Number _____ Exp. Date _____

Signature _____

Circle # 227

609

EXCEPTIONAL PARENT *Library*

PARENTING YOUR CHILD WITH A DISABILITY

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER

HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder
L. ADKINS & J CADY

Information about typical behavior characteristics; offers suggestions on how to foster the development of appropriate behavior.

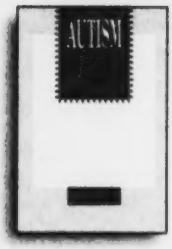
PE040AD **$5.00**

ATTENTION DEFICIT DISORDER: ADHD & ADD SYNDROMES (2nd Ed.)
DALE R. JORDAN

Guidelines for working successfully with ADHD and ADD in children, adolescents, and adults. For teachers, counselors, and parents.

PE038AD **$14.00**

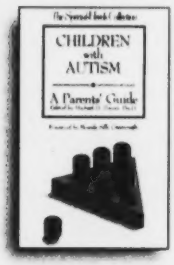
AUTISM



AUTISM
Information and Resources for Parents, Families, and Professionals
R. SIMPSON & P. ZIONTS

Resources book, presented in a question-and-answer format.

PE043OD **$24.00**



CHILDREN WITH AUTISM
A Parents' Guide
EDITED BY MICHAEL POWERS

A complete introduction to autism answers, questions, and gives hope to parents coping with this perplexing disorder.

WB017OD **$14.95**

OUT OF SILENCE
a journey into language
RUSSELL MARTIN

A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.

HH083AM **$22.50**

DISABILITY, GENERAL

THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM

A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.

HC082OD **$12.00**

CAN'T YOUR CHILD SEE?
A Guide for Parents of Visually Impaired Children
E. SCOTT, H. JAN & R. FREEMAN

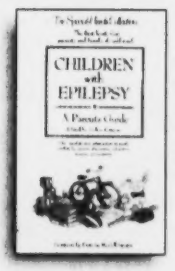
Practical guidelines for helping visually impaired children reach their full potential

PE041OD **$23.00**

CHILDREN WITH DISABILITIES: *A Medical Primer*
M. BATSHAW

For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.

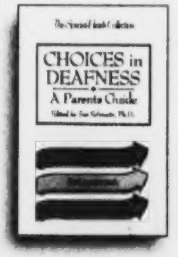
PB071OD **$29.00**



CHILDREN WITH EPILEPSY
A Parents' Guide
EDITED BY HELEN REISNER

Chapters on diagnosis, medications, daily care, family life, advocacy, and special education.

WB018OD **$14.95**



CHOICES IN DEAFNESS
A Parent's Guide
EDITED BY SUE SCHWARTZ, PH.D.

A clear, thorough, reassuring book that will help parents make the best choices. Written by professionals with frank personal accounts by parents.

WB025OD **$14.95**

COUNT US IN
Growing Up with Down Syndrome
J. KINGSLEY & M. LEVITZ

The authors share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship.

HB073DS **$9.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: *Directories of National Organizations, Associations, Products & Services.*

A valuable reference tool for parents and professionals.

EP055DR **$20.45**

HONOR THY SON
A novel by Edgar Award winner Lou Shaw

This unforgettable story combines suspense, terror and international intrigue—and a father & a son each pursuing a dream.

AB081OD **$12.95**

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE

Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER

Features chapters by parents, siblings and professionals

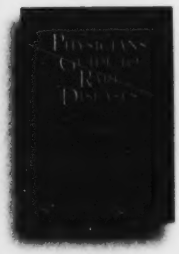
EP001EP **$14.95**

THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER

Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.

WB020OD **$14.95**

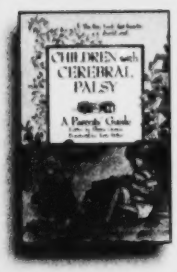
NOBODY'S PERFECT
Living & Growing with Children Who Have Special Needs
NANCY B. MILLER
Offers parents the strategies and emotional support to create a harmonious daily life and improved communication with family, relatives and professionals.
PB0520D **$21.00**



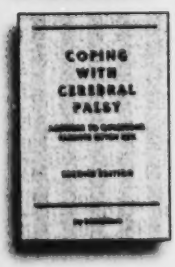
PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP0210D **$75.50**

PLANNING FOR THE FUTURE:
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP0240D **$24.95**

DISABILITY, PHYSICAL



CHILDREN WITH CEREBRAL PALSY
A Parent's Guide
EDITED BY ELAINE GERALIS
About CP and how it will affect a child and family. Written by doctors, therapists, educators, and parents
WB012PD **$14.95**



COPING WITH CEREBRAL PALSY: ***Answers to Questions Parents Often Ask***
JAY SCHLIECHKORN
Provides answers to more than 300 questions that have been carefully researched.
PE037PD **$24.00**

TAKING CHARGE:
Teenagers Talk About Life & Physical Disabilities
EDITED BY K.H. KRIEGSMAN
Explore the wide range of issues that teenagers with physical disabilities face as they approach adulthood.
WB013PD **$14.95**

TEACHING THE YOUNG CHILD WITH MOTOR DELAYS: ***A Guide for Parents and Professionals***
M. HANSON & S. HARRIS
Provides information to parents on how motor development influences other areas of development.
PE049PD **$27.00**

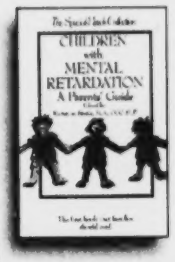
INJURY

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$5.00**

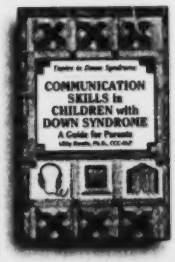
WHEN YOUR CHILD IS SERIOUSLY INJURED:
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$2.75**

MENTAL RETARDATION

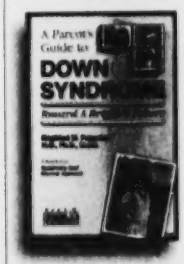
THE CHILD WHO NEVER GREW
PEARL BUCK
Brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation
WB008MR **$14.95**



CHILDREN WITH MENTAL RETARDATION
A Parents' Guide
EDITED BY ROMAYNE SMITH
Guide to everything parents need to know about raising their child and meeting their varied medical, therapeutic, and educational needs.
WB007MR **$14.95**



COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME
A Guide for Parents
LIBBY KUMIN
Parents learn how communication skills progress from infancy through the early teenage years.
WB031DS **$14.95**



A PARENT'S GUIDE TO DOWN SYNDROME
Toward A Brighter Future
SIEGFRIED M. PUESCHEL
Thorough overview of Down syndrome, to guide parents through the life span of their child.
PB051DS **$20.00**

TEACHING THE INFANT WITH DOWN SYNDROME
A Guide for Parents and Professionals
MARCI HANSON
Expanded thoroughly updated, written specifically for the parent of a Down syndrome infants, step-by-step guide.
PE048DS **$27.00**

Mail to: **Exceptional Parent,** Dept. EP9408, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total
NJ Residents 6% Sales Tax
Shipping
TOTAL

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date ____/____

Signature _____

CHILDREN'S PAGE

LIVING WITH MOEBIUS SYNDROME

by Natalie Abbott

I was born with a mild case of Moebius syndrome, a condition which affects the cranial nerves and causes facial paralysis. The whole left side of my face is immobile. My smile is lopsided and I can only move my eyes up and down, not side to side. I can't move my tongue very much, so it's kind of hard for me to eat, and I slurp a little too much. It is hard to drink from a straw because I can't move my mouth in a sucking motion.

As a result of Moebius syndrome, I have an asthma-like condition which involves shortness of breath, wheezing and coughing. I have had a lot of eye problems also. I have had two surgeries on my eyes—neither of which I remember—and I've worn sunglasses since I was two.

Moebius syndrome affects me a little bit in school, too. For one thing, I am not able to be alert during games in gym class. When we play tag, I often get tagged because I can't look around enough. In class, I have problems because the muscles in my hands are really weak. It hurts when I write for a long time. Sometimes, I get kind of annoyed when my teacher walks around the class while talking—the other kids can just move their eyes to follow her, but I have to move my whole head.

My mom did not tell me that I had Moebius syndrome until I was nine years old. I think it would have been easier on me if my mom had told me when I was younger. Before my mom explained it to me, I only knew was that I was different. I had started to feel self-conscious. Once I found out that my differences were caused by Moebius syndrome, it was easier to handle.

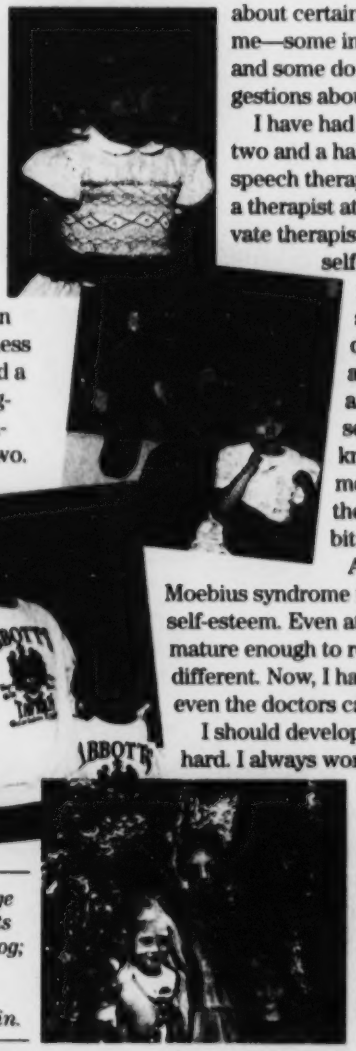
I go to a psychologist once a week. Mostly we play, but sometimes we have long discussions about certain things that are bothering me—some involve Moebius syndrome, and some do not. She tries to give me suggestions about my problems.

I have had speech therapy since I was two and a half years old. Now, I have speech therapy twice a week—once with a therapist at school and once with a private therapist. Recently, I started to feel self-conscious about going to my speech therapist away from school. My speech therapist's office is right on a main street, and there are a lot of people around. I think, "What if a person I know sees me here?" I know that nobody will tease me about going to a speech therapist, but I still feel a little bit afraid and self-conscious.

As a pre-teen, I think that Moebius syndrome is really starting to affect my self-esteem. Even at nine and ten, I was not mature enough to realize that I was really, really different. Now, I have all these questions that even the doctors can't answer.

I should develop more self-esteem, but it's hard. I always worry about things like whether people will understand me when I talk.

Moebius syndrome has really affected me. I've been different all my life, and for a long time, I didn't know why. If I didn't have this syndrome, I think I would be a totally different person. Having Moebius syndrome has given me more self-awareness and I've matured faster because of it.



[From top] *Natalie, age three; Natalie, 6, meets Clifford the big, red dog; Natalie and Dad; Natalie, 11, with cousins Jade and Colin.*

Natalie Abbott, 11, lives in Piedmont, California with her parents, Marcia and Wayne, and her cat. She has no siblings, but enjoys playing with her nine cousins. In September, Natalie will begin sixth grade at Piedmont Middle School.

612

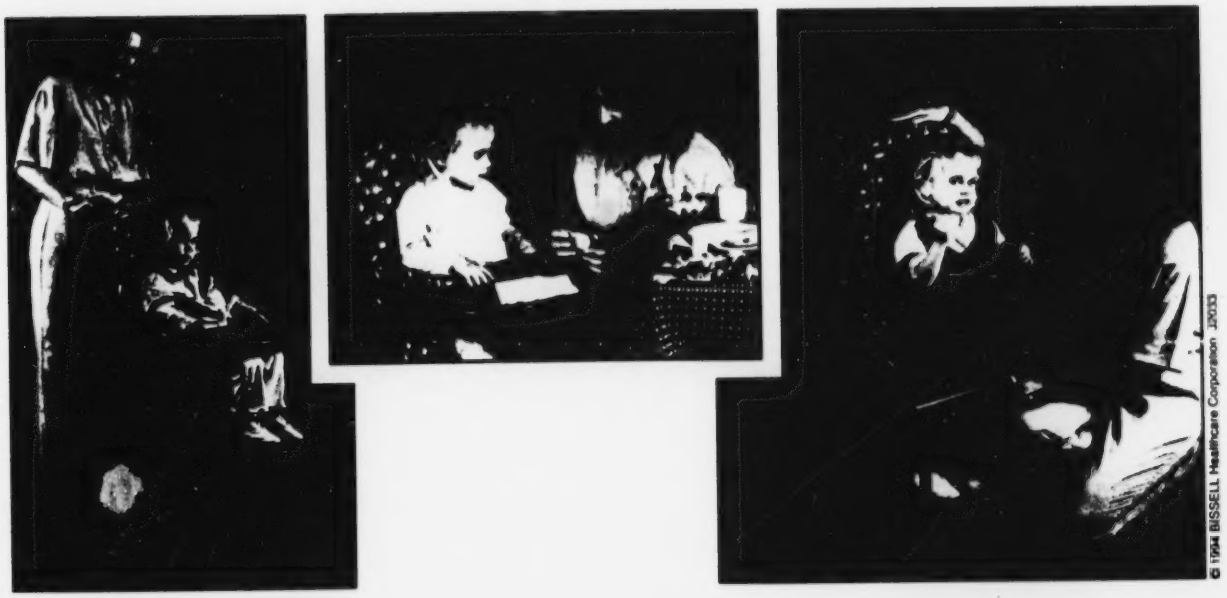
MENTOR'S PEDIATRIC PROGRAM

Mentor Urological has patient education materials available to educate patients, parents, and care-givers on bladder care products and their usage.

- *SELF CATH PEDIATRIC AND ADOLESCENT CATHETERS*
- *VIDEO GUIDE TO INTERMITTENT SELF CATHETERIZATION FOR BOYS AND GIRLS*
- *MENTOR PEDIATRIC CLOCK*
- *TOOBIE COLORING BOOK*
- *PARENT GUIDE TO INTERMITTENT CATHETERIZATION*
- *SELF CATH ACCESSORIES*

FOR INFORMATION OR SAMPLES, CALL CUSTOMER SERVICE 800-328-3863

Quick Change



© 1994 BISSELL Healthcare Corporation J2003

Imagine an infant stander so adaptable it can change its appearance instantly to become a stroller or even a highchair. Tumble Forms®, a leader in early intervention products, now introduces the Chameleon™.

Perfect for home or school use, the Chameleon accommodates children from 25 to 37 inches and up to 50 lbs. With this one lightweight unit, you can create numerous vertical, prone, and supine positions, for sitting, lying, or standing. The seat, seat back, and foot support each adjust for infinite possibilities. Meanwhile, the child is cradled against cushioned supports to ensure proper body alignment. You get three versatile products – stander, stroller and highchair – all for the price of one.

The Chameleon features a removable tray to allow easy transfer as well as swivel casters for portability. Breathable fabric covers are conveniently removed for laundering.

Leave it to Tumble Forms to change the way you view standers.

For more information, call 1-800-631-7277. In Canada call 1-800-665-9200.

Chameleon™ by Tumble Forms®

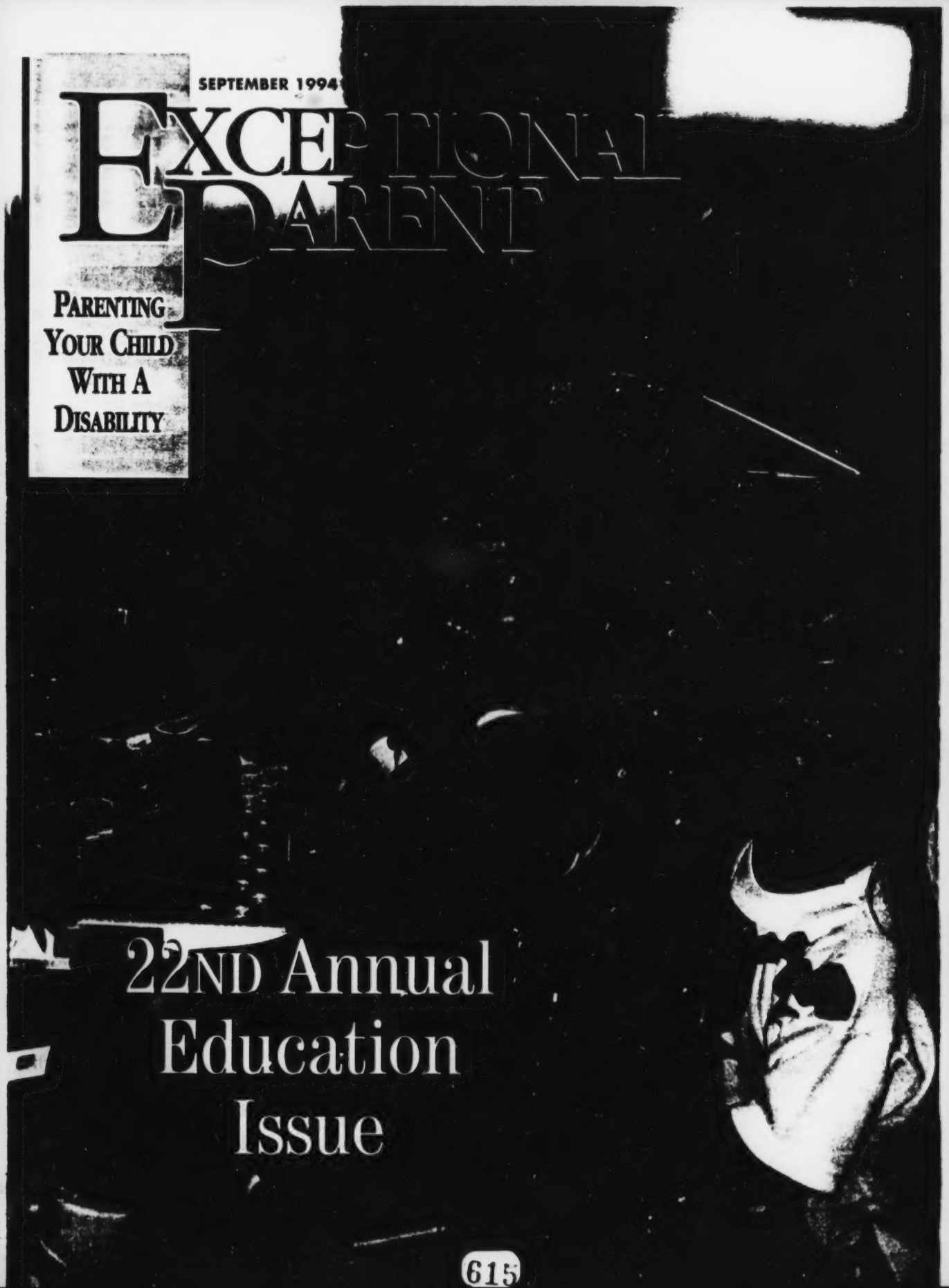
614

Circle # 7

SEPTEMBER 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY



22ND Annual Education Issue

615

FORD MOBILITY MOTORING MAKES LIFE MORE REWARDING!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created ... to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

A Smoother Road to Travel

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone and Roadside Assistance[1] for the duration of the bumper-to-bumper limited warranty.

Ford
MOBILITY MOTORING
PROGRAM

Information You Need ... for Informed Decisions

The Ford Mobility Motoring Program also provides ...

- friendly toll-free and special "TDD" ... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period

October 1, 1993 — September 30, 1994

Customer is responsible for a 12¢/day maximum activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.

Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, 4 Series Preferred Care or Red Carpet Lease plans have additional benefits.

A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!

Ford
Ford and Lincoln-Mercury Divisions

Circle # 30

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

SEPTEMBER 1994
VOL. 24, ISSUE 10

The First Day of School by Janneane Randall 35
Andy heads off to first grade at his neighborhood school.

Sibshops: Workshops for Siblings of Children With Special Needs by Donald J. Meyer 47

Halloween Magic by Juanita Stotts 50
How to make a wheelchair part of a Halloween costume.

Cut From the Same Bolt of Cloth by Nancy Holroyd 55
Abby's escapades help Sheila's mother gain a new perspective.

Dental Care for Children with Disabilities by Steven P. Perlman 57
Brushing, Flossing and Rinsing.

COVER:
Five-year-old Benjamin Stotts and his sister, Rachel live in Mesa, Arizona. In this issue, Ben's mom, Juanita, shares plans for making a wheelchair part of a Halloween costume. See page 50.

EDUCATION

1994 Educational Program Awards 36–44

Inclusion: What It Is, What It's Not, and Why It Matters by Dorothy Kerzner Lipsky and Alan Gartner 36

Inclusion and Ideology by Albert Shanker 39

A National Agenda For Achieving Better Results by Thomas Hehir 41

Making Inclusion Work by Janine Guida, Stephanie Pirsos, Katherine Schempp and Diana Cuthbertson 43
Angela is supported by a circle of friends.

DEPARTMENTS

Editor's Desk 2
Letters 4
Search & Respond 10
Familiar Faces 21
Ask the Doctor: RESPIRATORY PROBLEMS 22
Health Insurance Troubleshooter: MEDICAID MAZE 26
Role Models: ABRAHAM NEMETH 31
Fathers' Voices: DEAR TIMMY... by Wayne Stauffer 53
Media: COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES 64
Directory of Advertisers 67
What's Happening 72
New Products 76
Children's Health Notes 77
Exceptional Parent Library 82

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year, $30 per year to organizations, schools and agencies. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

EDITOR'S DESK

Since *Exceptional Parent's* first issue in 1971, we have advocated for the existence of a range of good educational choices for all children. Because we believe that parents are the best experts on their own children, we have published a number of articles by parents who have made a variety of different educational decisions for their children. Our failure to "take sides" has been criticized both by proponents of inclusive education and those who support relatively separate educational programs for some children.

STANLEY D. KLEIN, PH.D.

As I listen to arguments about educational choices, I am reminded of a boy I once knew in the days before the major legislation to provide a free, appropriate, public education for all children with disabilities. This boy was in a special class for children with mental retardation in a public school in his neighborhood, an impoverished urban area. He had been placed there solely as a result of his score on an intelligence test—that was the way placement decisions were made in those days. I was asked to review the this placement because some people thought the boy should not be classified as "mentally retarded"—especially because his IQ score was just below the cut-off point that was rigidly applied to determine class placements.

I visited the boy's school to observe the special class in which he was currently placed and the regular classroom in which he would be placed if it were determined that he was not "mentally retarded." The special class had a small number of students and a talented teacher who had extensive training in special education. The boy was flourishing in this placement, both academically and socially.

In contrast, the regular classroom was a chaotic, overcrowded environment. The teacher was overwhelmed, and had no supports. Because it was hard to imagine that such a classroom would be appropriate for any child, I recommended that the boy remain in the special class. I wish more choices had been available.

Educational Program Awards

Our 17th Annual Education issue—September 1989—brought the first *Mainstreaming Contest*, honoring educational programs nominated by readers. Last September, the award was presented to a good example of *School Inclusion*. This year, in the interest of promoting *good* educational choices rather than any specific type of placement, the award was renamed the *Educational Program Award*.

We received far more nominations than ever before. This year's awards go to a variety of different programs—individual inclusive schools, a statewide inclusion plan, a private "special education" school and a group of parochial schools.

Winners are profiled within a series of articles which present different perspectives on educating children with disabilities. Also within this section is an article which illustrates the hard work and planning necessary for *Making Inclusion Work*.

At the White House

Assistant editor Kim Schive and publisher Joe Valenzano were at the White House on July 27 for a celebration of the fourth anniversary of the Americans with Disabilities Act (ADA). President Bill Clinton, Hillary Clinton, Vice President Al Gore and Tipper Gore addressed the group gathered on the South Lawn. While celebrating the ADA's many contributions, all of the day's speakers emphasized that health care reform would play an essential role in removing still-existing barriers to employment for people with disabilities.

Young Contributors

We need more submissions for our *Children's Page*. This is an important feature of the magazine. We encourage contributions from children with disabilities, their siblings and their friends. Be creative! Send stories, photos and artwork to *Children's Page, Exceptional Parent*, 209 Harvard St., Suite 303, Brookline, MA 02146-5005.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology, New England College of Optometry

ASSISTANT EDITOR Kim Schive

EDITORIAL STAFF
Marc S. Malkin Valerie Steele

EDITORIAL INTERNS
Jennifer Fisher Ludmilla Panza
Sara Wood Pyongson Yim

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Sutera

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferrante

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (CO, IN, KS, MN, ND, No OH, SD, UT, WI)
Anthony Arnone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, MI, MO, NB, So OH)
John Maisel
(708) 416-0780 Fax (708) 416-0793

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
William Hague
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESIDENCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58. BPA International Consumer Magazine Membership Applied for August 1993.

618

Report

Outcomes: Posture, function, and [illegible] improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Joy GS: Simple, cost-effective children's seating.

LETTERS

Viewpoints on Inclusion

I read Dr. Edwin Martin's guest editorial, *Inclusion: Rhetoric and Reality* (April 1994), with interest. I have just been through a due process hearing whereby I sought residential placement for my son, Charles. Currently, our case is in the United States District Court. By the end of these proceedings, we hope to discover what it takes to get "residential placement" on a child's IEP—the criteria for residential placement are ambiguous at best.

In the course of pursuing the due process procedure, we have spent almost as much as a single year's tuition at the school where he is now a resident. So far, the only clear winners are the attorneys and consultants involved in the case.

While the trend toward inclusion is admirable and noble, it hurts those children, like my son, for whom residential placement is appropriate. Holding to the standard that a school district's program need only provide "some educational benefit" unfairly penalizes children who need 24-hour, seven-day-a-week continuity and structure.

J.R.W., Alabama

☐ Parents should be encouraged to make the educational choices they feel are best for their children. Although other parents or various professionals may not agree, we must remember it is our choice, not theirs.

Two of my daughters have attended special programs for children with mental retardation. In my opinion, it was the best program for the girls. Inclusionists have forgotten the true meaning of "least restrictive environment." If a child has needs that cannot be met—and I mean all their needs, including acceptance and respect—then they are not in the right placement. I believe in community integration and equal opportunity, but children also need places where they are wanted and loved, not ridiculed.

As a blind child in the 1950s, I was privileged to attend Catholic schools. This was a good experience academically. Socially, it was not.

I certainly believe that our children should be mainstreamed when possible. But, when teachers are not properly trained, materials are not available or children have additional disabilities, inclusive settings can be *more* restrictive. Parents should be encouraged to make the choices they feel are best for their children.

C.R., Ohio

☐ I would like to share my experience with inclusion. My son, J.J., is an eight-year-old boy with autism. Because of severely aggressive behavior, he has been in a residential placement for four years. We wanted him home, but felt we could not offer him the structured environment he needed.

After hearing so much about inclusion, we decided we should give our son a chance. It lasted three months. My son did not stop being autistic at 3 p.m. when school let out. He did not stop being autistic during school vacations. His behavior deteriorated badly. Although "professionals" told us we were failing our son, we sent him back to the residential school where he could have the ongoing structure and consistency he so desperately needs.

Inclusion may be wonderful for some children. For us—and more importantly, for my son—it was a nightmare. "Residential" is not a four-letter word!

D.B., New Hampshire

EXCEPTIONAL PARENT

Support, Voice, Guide, Vital & Empower

▸ *To reach out to parents of children with disabilities and special health care needs.*

▸ *To empower mothers and fathers by providing practical information and emotional support.*

Editorial Advisory Board

LISA BLUMBERG, J.D., Corporate Attorney, Aetna, Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Waltham, MA
SANDRA B. FLEISHMAN, Parent, Project Director, A WORLD OF DIFFERENCE Institute, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, Pomona, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President Emeritus, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

620

RICON

Innovation in Mobility

Everyday Heroes

Protected By Our 5-Year PEACE-OF-MIND Limited Warranty

For more information about Ricon wheelchair lifts, call

1-800-322-2884

United States • Canada • United Kingdom • Norway

Ricon Corporation 12460 Montague Street Pacoima CA 91331

(818) 899-7588 Outside U.S. • (818) 890-3354 Fax

Circle # 65

A "Happy Issue"

Halfway through your July issue, I found myself checking my checkbook to make sure I had renewed my subscription. I had thought, several times, that I would not do so.

I hope this issue was just the beginning of a new *Exceptional Parent*. The many "personal glimpses" and personalized articles made this issue a gem!

Our children are different. Many are ill—my littlest died in December and is missed *so* much—but they are loved. We need and value the information you provide, but we also need the "perks" of seeing how other "real people" live, love and cope. Here's to your "happy issue."

C.B., California

Familiar Faces

I have been an avid reader of *Exceptional Parent* for more than two years. I really enjoy the recent addition of the *Familiar Faces* page. Thank you for continuing to publish an excellent magazine for parents such as myself.

J.T., California

Readers Speak Out

EXCEPTIONAL PARENT recently published a letter entitled "Magazine is Less Useful" (May 1994). The writer (E.M., Texas) criticized the magazine for failing to include enough articles by parents; she felt that recent issues had placed too much emphasis on political advocacy and inclusion. E.M. also disagreed with the magazine's policy of publishing only the initials and state of letter writers; she asked that readers be given the option of using full names and addresses.

I agree completely with E.M. I have written to you several times to express my desire to network with parents; your policy hinders that. If parents do not want to publish their names or addresses, let that be their choice. We are all "grown-up" enough to handle mail solicitors. I deal with that every day!

I also agree that not all of us are on the inclusion bandwagon. Our choices should be respected, too.

Thank you for putting parents in touch with one another. I cannot think of a greater purpose. In numbers we will find strength. To correspond with a parent who knows my pain is the best gift you could offer.

L.B., no address given

☐ First of all, I don't care if you print my name or initials. I think you have done both over the years I have been writing to you. All magazines have the right to set their own editorial/stylistic policies. I wasn't aware that this publication was run by popular consensus. Go ahead and do what you will with the names/initials on letters.

Perhaps E.M. is being defensive because the general trend of the more progressive thinkers in the field of special education—parents and professionals alike—is to move away from segregated placements for children with disabilities. I think it is part of *Exceptional Parent's* responsibility to keep up with changes and movements within the field.

I am glad *Exceptional Parent* is reaching out more to "politically active parents." They are the ones who helped to push legislation through Congress which now guarantees our children a free, appropriate, public education. The political is the personal; the personal is the political. Our children's options in life will be shaped by the political process. It is foolhardy to think that we can opt out of it.

Actually, E.M.'s letter helped me to clarify my thinking about the magazine. I knew that I had started reading *Exceptional Parent* a lot sooner after it arrived and reading a lot more of the articles. Now, I know why. The magazine has become more politically aware and more scholarly, and therefore, a lot more interesting to me. I can live without maudlin parent testimonies about how their children with disabilities changed their attitudes toward God and their religion and how it made them better people.

Please, *Exceptional Parent*, continue to be political, scholarly and useful to me.

J.L., California

☐ I specifically disagree with E.M. from Texas. I am the mother of a gifted adolescent with learning disabilities and attention deficit disorder. I had previously let my subscription lapse because I was not able to relate my son's situation to the magazine articles. I wasn't finding the magazine very helpful or relevant to our family. I am finding *Exceptional Parent* much more relevant and supportive this year.

K.M., Rhode Island

☐ I would like to add my vote for publishing names and addresses in the *Search* section. I have always felt it was a bad move to stop doing that. It seemed like yet another example of the disability professionals putting as much distance as possible between parents. We parents desperately need each other. I have long puzzled over and resented being kept away from other parents artificially—"for my own good." Yeah, right.

Parents with knowledge are parents with power. They are thorns in the sides of disability professionals. This gives professionals a vested interest in keeping parents apart. I was very disappointed when *Exceptional Parent* bought into that idea. I thought it was a magazine *for* parents!

I also must say that in general, *Exceptional Parent* is excellent. I have learned from, laughed at and cried over articles you have published. Keep listening to parents—that will keep you on track.

M.D., Michigan

EDITOR'S NOTE: We appreciate the many thoughtful letters we received in response to E.M.'s comments. We agree that letter writers in this section should be given options about how to identify themselves. From now on, writers of letters to the editor will have the option of being identified by initials and state; full name and state; or full name, city and state. When no preference is stated, we will continue to use initials and state.

On the other hand, we will continue to identify writers of SEARCH letters only by initials and state, and to forward responses through this office. This decision has nothing to do with a desire, as M.D. put it, "to keep parents apart." On the contrary, we are thrilled by the fact that so many parents have found each other in the pages of this magazine over the years. But being able to handle responses allows us to select a representative sample to publish in RESPOND, allowing many readers to benefit. It also gives us another avenue of insight into our readers' interests and con-

A River Runs Through It.

Introducing the River Tank Ecosystem.®

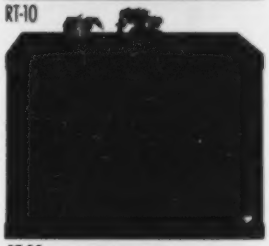
Your fish have been dreaming of this. A playground of sorts where they move up and down the rapids and waterfalls. And where they travel from pool to pool as they do in a natural river habitat.

Maybe you've been dreaming of this. A tank you never have to empty. A tank that let's you use real plants above and below the water. A tank that's entertaining and educational. A tank that requires little maintenance.

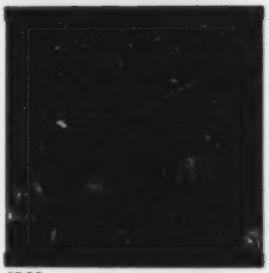
It's not an aquarium. It's not a terrarium.

The patented River Tank Ecosystem is a dynamic, living habitat where plants, fish, frogs and reptiles interact in ecological balance.

RT-10



RT-20



RT-30

Like a real river, the rushing water generates a healthy, oxygen-rich environment. When the water seeps through the gravel-filled plant cavity, biological balance is naturally maintained. And since plants use fish waste as food, there is no need for fertilizer.

There's a River Tank for every environment.

Homes. Schools. Workplaces. Now everyone can have a river view. The River Tank is available in four sizes: RT-10, RT-20, RT-30 and RT-45. It's very affordable. And you don't need a life preserver to enjoy it.

Call 1-800-808-8822 for more information or the dealer nearest you.

RIVER TANK SYSTEMS

PO Box 445, Exeter, RI 02822

Circle # 251

ABDC is your link to parent partners

The Association of Birth Defect Children (ABDC) is your link to parent partners, birth defect information, newsletters, fact sheets, and support referrals. Link with families of children with similar disabilities through ABDC's National Birth Defect Registry.

To receive a free parent matching registry packet and information about ABDC's other projects and services call: 1-800-313-ABDC (24 hours a day)

☑0853 During the Combined Federal Campaign in your workplace.

Circle # 218

cerns; this helps us to plan the content of future issues.

Finally, in hopes of allowing more parents—and children—to find each other, a pen pals page will soon become a regular part of EXCEPTIONAL PARENT. *See below.*

Pen Pals

As a result of many requests from readers, we will begin a Pen Pals Page in an upcoming issue.

If you are an adult seeking a pen pal, send us your name and address along with two or three sentences to introduce yourself and explain the type of pen pal you would like to find. Please include a daytime telephone number (where we can reach you; it will not be published).

Children's pen pal requests should include the above information plus the child's age and sex, the daytime phone number of a parent and a parent's signature confirming permission to publish the child's request.

Here's one to start with:

Scott Richards
RR #1, Box 1889E
Whitefield, ME 04353
Age 9, male. Has brother with Coffin-Lowry syndrome; likes rock-collecting and karate. Wants to hear from anyone.

Send pen pal requests to: Pen Pals, *Exceptional Parent,* 209 Harvard St., Suite 303, Brookline, MA 02146.

Designed for the Development of Functional Skills!

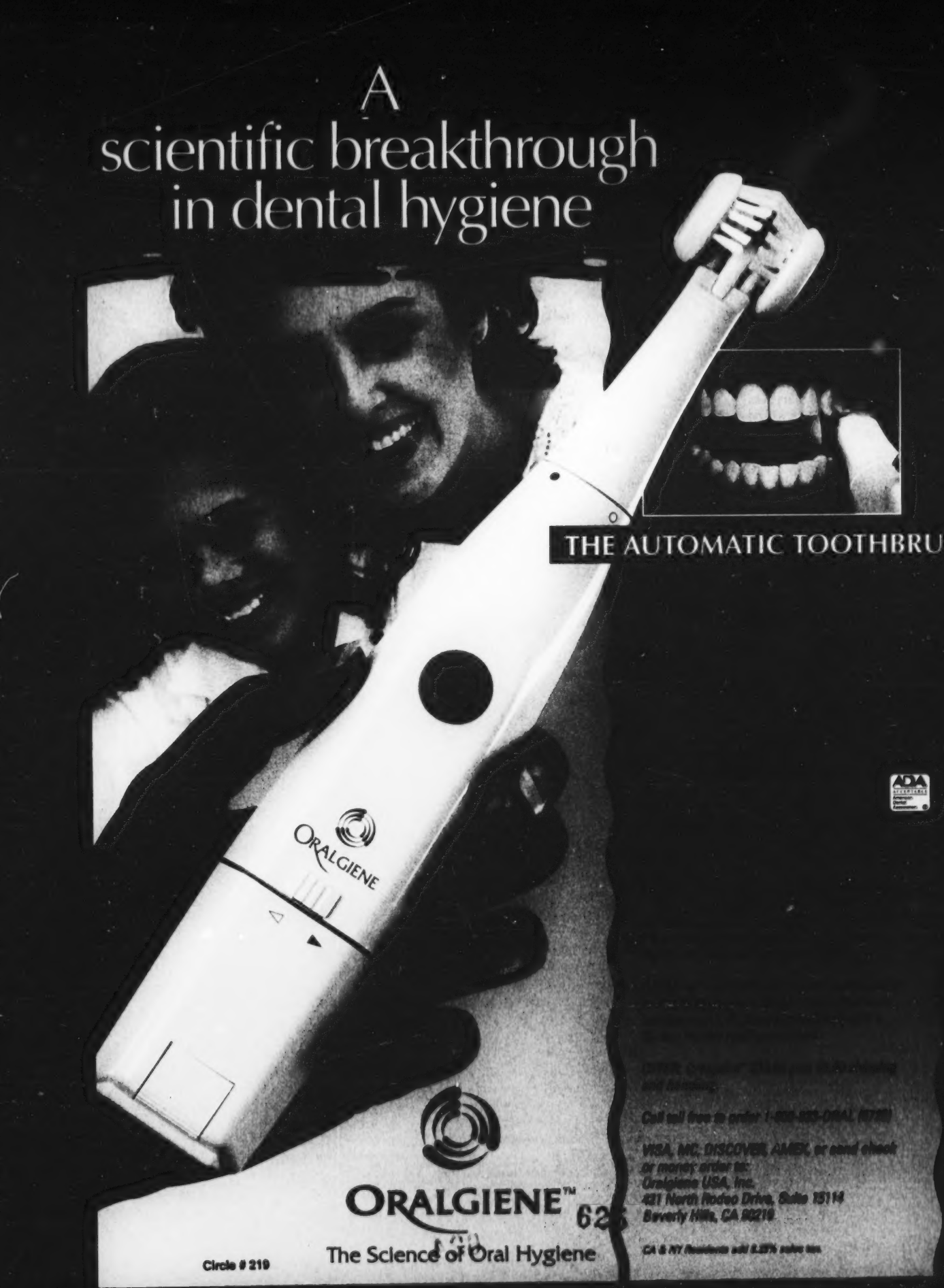
The Mulholland Growth Guidance System™ is a fully integrated Postural Support System. All components are designed to interact with therapy objectives in the acquisition of head and trunk control, dysphagia training and fine motor skill development. Available with **Tilt in Space** and **Crash-tested for Car Seat and Van/Bus Use.**

For More Information Contact:
Mulholland Positioning Systems, Inc.
P.O. Box 391, Santa Paula, CA 93061
(800) 543-4769 FAX (805) 933-1082

Circle # 52

624

A scientific breakthrough in dental hygiene



THE AUTOMATIC TOOTHBRUSH

ORALGIENE™

The Science of Oral Hygiene

Call toll free to order 1-800-333-ORAL (6725)

VISA, MC, DISCOVER, AMEX, or send check or money order to:
Oralgiene USA, Inc.
421 North Rodeo Drive, Suite 1511
Beverly Hills, CA 90210

CA & NY Residents add 8.25% sales tax

Circle # 219

SEARCH

Community Involvement

My son is a delightful nine-year-old with attention deficit hyperactivity disorder (ADHD), auditory processing disorder and secondary autistic tendencies. He has just completed a year of supported inclusion in second grade. Academically, he did fine. Socially, however, the year was abysmal. He was never invited to birthday parties or play dates. We tried Cub Scouts and a swim team. Other children avoided him. Involved adults were patronizing but intolerant. My husband and I offered our help in all extracurricular activities.

We have tried everything to get our son involved in our community but have met with no success. I would appreciate suggestions from parents who have been successful in involving their children in their communities.

J.R., New Jersey

Werdnig-Hoffmann Disease

Our five-year-old son, Daniel, was diagnosed with Werdnig-Hoffmann disease (spinal muscular atrophy, type I) at 12 months. At age two, he was diagnosed with a seizure disorder and had a feeding tube inserted. He has been hospitalized frequently due to aspiration pneumonia.

Daniel cannot roll over, sit up, crawl or walk. However, he has an electric wheelchair and is very mobile. He can still control his arms and hands. He is exceptionally bright.

My husband and I would like to hear from anyone who has information on or experience with this disease.

B.O., Rhode Island

EDITOR'S NOTE: Families of SMA (P.O. Box 1465, Highland Park, IL 60035-7465, 800/886-1762) can put you in touch with other families of children with this condition.

Catheterization?

I am the mother of a three-year-old who has been diagnosed with cystic periventricular leukomalacia. She has cerebral palsy, infantile spasms and is tube-fed.

She has had recurrent urinary tract infections and is currently on Bactrim, in hopes of preventing further episodes. After she had a cystogram, our doctor advised us that we will have to start catheterizing her intermittently. Her bladder is extremely small and does not empty out totally.

We are very discouraged and hope that someone can provide alternatives for us. We don't know if there are other options besides catheterization.

C.M., California

Unsure About the Future

My three-year-old son, Nevada, was born at 31 weeks weighing three pounds, fourteen ounces. He has been diagnosed with bronchopulmonary dysplasia, bilateral spastic hemiplegia, hydrocephalus, asthma, central nervous system damage/dysfunction, oral-motor dysfunction and a seizure disorder. He has a tracheotomy, VP-shunt and g-button. He is oxygen-dependent.

Despite his many problems, Nevada is an alert, happy and social child. He seems to understand what is going on around him and is starting to talk. He can sit and stand with assistance. Although Nevada does not take any nutrition by mouth, he is starting to taste different foods.

I have always been an advocate for full inclusion, and I try to include Nevada in as many social activities as possible. Next year, he will be starting in the regular preschool program at our local school. My husband and I try to treat him as though he does not have disabilities.

I would like to hear from other parents who have a child, Nevada's age or older, who has similar disabilities. I feel unsure about Nevada's future as far as school, feeding, family attitudes and social activities.

B.L., Kentucky

Severe Disabilities

I would like to correspond with other parents who have a child with severe disabilities. My 10-year-old son has autism and mental retardation. He is still in diapers.

I have rheumatoid arthritis. On a "bad day," caring for my son is quite a challenge. I would like to be able to write a letter to someone who can identify with what I am going through.

L.B., Arizona

Undiagnosed

Our one-year-old daughter, Marissa, is developmentally delayed. To date, her main symptoms have been severe hypotonia (low muscle tone) and, recently, myoclonic seizures involving her arms and eyes. At six months of age, she had two seizures and has been on Phenobarbital since, with no more occurring. Her vision was poor, but seems to be improving as she gets older. She is very tall for her age—almost 34 inches long, putting her at the 110th percentile for her age.

Marissa has had the following evaluations and analyses: cranial MRIs, EEG, bone-age, lumbar puncture, urine and plasma amino acids, urine organic acids, EMG, muscle and nerve biopsies, thyroid hormone levels, ammonia, lactate, pyruvate, calcium, very long fatty acids, creatinine kinase and high-resolution metaphase chromosome examination. All were normal except that the muscle biopsy showed thicker-than-normal mitochondria. Biochemical studies, however, showed normal enzyme levels. A DNA study on her

Search and **Respond** is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

626

You Asked DynaVox To Do Even More...

"I want to tell a story."

"I want to spell and talk faster."

"I want to communicate faster with my associates."

Introducing DynaWrite.

DynaVox Was Just The Beginning.

When we first introduced the revolutionary new DynaVox™ augmentative communication aid, the response was overwhelming.

Because people found that DynaVox's modern, user-friendly technology was so much easier to learn than old-fashioned codes, most of them could begin using it in less than half an hour.

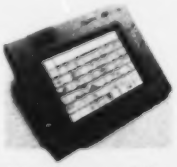
In fact, DynaVox made everyday communication so enjoyable, they wanted to go on to even greater challenges.

Introducing DynaWrite.

That's why we've created DynaWrite™, the new software package for DynaVox that helps people compose longer, more complex messages, faster and easier than ever before.

DynaWrite uses a form of artificial intelligence called "word prediction," which *analyzes* as you write, and offers logical choices for the next word, based on the rules of grammar and a built-in 40,000-word dictionary.

Users can select from these choices with a single keystroke, so they can compose messages twice as fast as with ordinary letter-by-letter typing.



Finished compositions can then be saved, reloaded, and re-edited as needed, and spoken by the DynaVox, or output to a printer.

Dedicated To Communication.

And because the DynaVox is a totally self-contained *communication* aid, you get all this capability without having to buy a separate computer and speech synthesizer, or learn specialized computer skills.

No other single device can offer the complete spectrum of communication — from symbols, written words, and advanced word prediction, to the highest quality synthesized speech in the world. So no other device can offer the value DynaVox can.

A Straightforward Commitment.

And that's no accident. It's a direct reflection of our commitment to augmentative communication. Because we know it takes more than just technology — it takes a thorough understanding of language, continuing support, and practical, affordable solutions — to keep pace with your growing needs.

So if you know someone who might benefit from the DynaVox — and from new DynaWrite software — we urge you to contact your therapist. Or give us a call at **1-800-344-1778.**

We Hear You.

SENTIENT SYSTEMS TECHNOLOGY INC.

Circle #68

muscle tissue was also normal.

Marissa can roll from her stomach to her back and from her back to her stomach. She is just starting to scoot on her tummy. When prone, she can lift her head for one to two minutes. Her fine-motor skills are at a four-to-five-month level. Her fine- and gross-motor skills seem to be progressing, but at a slow pace. She is still very floppy.

Marissa eats well, and is alert and good-natured. She is starting to make some sounds, but does not babble.

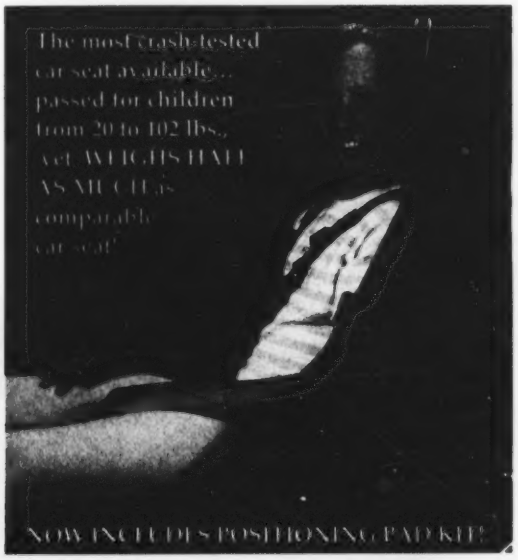
We feel very frustrated that she cannot be diagnosed. The doctors keep telling us that we have to wait to see if new symptoms appear. I feel that there has to be somebody out there with an answer and a diagnosis. We would like to hear from anyone who knows of a similar child.

L.B. & M.B., Minnesota

Super ***Light****, Super* ***Strong****, Super* ***Safe****, Super* ***Simple****...the Columbia Car Seat has been the #1 choice since 1986* Thousands of Columbia Car Seats are now in use, and we have received some amazing crash stories. One grateful father in Louisiana sent a picture of his badly crumpled van and said, "My 4-year-old son escaped without a scratch, did not even break his glasses." One mother in Colorado wrote, "Thank you for making such a wonderful car seat! I really like how comfortable [my son] is in it. On Dec. 5, 1991, we were hit extremely hard on the passenger side. My 6-year-old son, a healthy 65 pounds, was not hurt at all because your car seat held him so securely."

Our years of *real world* experience give you peace of mind knowing your child is comfortable and secure in our seat!

PLUS it's light-weight, easy to use, good-looking and easy to care for!



Ask for our FREE Full Color Catalog of convenient, helpful products

The Columbia Car Seat is your best value!

- The LIGHTEST special car seat–easy to handle!
- Fits easily into ALL vehicles, no matter how compact!
- EXCEEDS all Federal safety standards!
- Approved for car, school bus and even airplane travel!
- Fits your choice of 4 stroller bases!

MEDICAL MFG. CORP.
(800) 454-6612
Dept C1, P.O.Box 633
Pacific Palisades, CA 90272

Circle # 11

Progressive Neurological Disorder

My 14-year-old son, Michael, has been diagnosed with familial spastic paraparesis. Doctors have told us this is a "wastebasket" diagnosis they use for unknown disorders. We have searched without success for a diagnosis so we can better prepare for his future. We know he has a progressive neurological disorder that involves the white matter of the brain and the myelin.

Mike's development seemed normal until he was about three years old. In preschool he was unable to cut, paste, color or put on his snow-pants or boots. Between the ages of three and four, he started to walk on his toes. Then, he began dragging his right leg. Since age 10, he has been unable to walk independently. Now, he cannot stand independently. He uses a motorized scooter and wheelchair. He is no longer able to write, and his speech has deteriorated to a point where he is almost impossible to understand.

Mike has just completed seventh grade in a regular classroom. He is of average intelligence, although he is below grade-level in some subjects. He has a full-time aide in school.

Mike has undergone numerous tests. All have been normal except the MRI which shows decreased myelin of the white matter of the brain. I would appreciate hearing from anyone whose child has a similar condition.

P.B., Wisconsin

EDITOR'S NOTE: The United Leukodystrophy Foundation (2304 Highland Dr., Sycamore, IL 60178, 800/728-5483) can put you in touch with families of children who are similar to your son. They may also be able to help you obtain a more specific diagnosis for his condition.

Johanson-Blizzard Syndrome

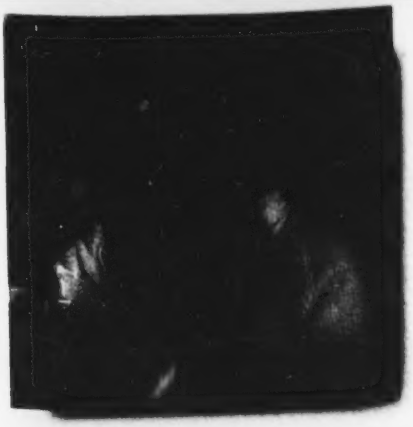
I'm a mother of a beautiful 11-month-old boy named Joey, who was born with a rare condition called Johanson-Blizzard syndrome.

The syndrome causes pancreatic malfunction, imperforate anus, deafness, hypothyroidism, dwarfism, absence of permanent teeth, malabsorption, aplasia of the alae nasi (absence of nostril openings), mental retardation and developmental delays.

Joey receives physical and occupa-

628

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.



AND THEN BACK OUT AGAIN."

At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

P-CAP

CHRYSLER CORPORATION

For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Circle #629

THE TUNED-IN, TURNED-ON BOOK
About Learning Problems
-Revised Edition-

Help your child learn how to work around learning disabilities

In this best selling self-help guide written directly to adolescents and teens, author Marnell *Hayes, Ed.D.,* takes a positive and practical approach to helping kids capitalize on their individual learning style.

The content of the new edition now includes new study tips, a new glossary, and more 'homework' for parents and teachers to help them understand what a child with learning difficulties needs them to know.

TUNED-IN, TURNED ON BOOK About Learning Problems
6x9" softcover, 163 pp. #090-1 $10.00
PREPAID: Add $2.50 s/h BILLED: Add 10% s/h (min. $2.50)
California residents add sales tax.

ACADEMIC THERAPY PUBLICATIONS
20 COMMERCIAL BLVD. NOVATO, CA 94949-6191
1 (800) 422-7249 Fax: (415) 883-3720

Circle # 244

Agape Village

helps develop happy, fulfilled people by promoting self-worth and self-sufficiency.

Agape Village, a residential community for mentally retarded/intellectually disabled adults, provides a learning atmosphere in which a highly qualified professional staff offer Villagers opportunities for success in

- learning home living skills and money management
- vocational and job training
- social/emotional growth
- physical fitness and recreation
- spiritual growth and church participation

Contact: Glenda B. Wallace, Ph.D., Agape Village
3711 Agape Village Rd., Macon, GA 31210, 912-471-3700

Circle # 245

SEARCH

tional therapy. He is unable to sit up or crawl, but is able to roll over.

I have had a difficult time finding current research and information. I'm interested in talking with any other parent who has a child with this syndrome.

D.L., North Carolina

Neonatal Herpes Encephalitis

Our six-year-old son has bilateral temporal lobe damage as a result of neonatal herpes encephalitis.

Jimmy does not process sound, so he does not speak. He also has epilepsy and mental retardation. He is considered hyperactive and has been placed in a program for children with autism. We would like to communicate with other parents or caregivers who have had experience with children who have been affected by neonatal herpes encephalitis.

B.W., Michigan

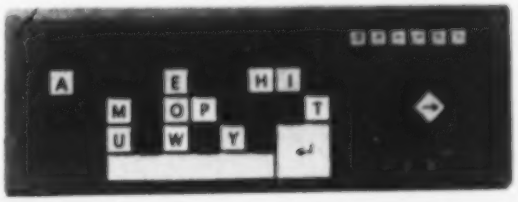
Trisomy 4p, Monosomy 5p

My beautiful, 20-month-old daughter has been diagnosed with a chromosomal unbalanced translocation resulting in trisomy 4p, monosomy 5p. She has significant developmental delays and is visually impaired. I would like to correspond with any parents of a child with this diagnosis.

H.H., New Jersey

Little Fingers need Big Keys!

..Introducing KID KEYS..
The keyboard for early learners.



KID KEYS is designed with the alphabet and numbers in mind. It makes your computer more user friendly and FUN for the earliest computer users!

- BIG COLORFUL 1 inch alphabet and number ordered keys are easy to find.
- Plug compatible with PC/XT and PC/AT computers. Requires no additional software.
- "Co-Pilot" cable available. Allows simultaneous use of two keyboards. An ideal tutoring tool.

Key Concepts 1-800-293-5090
Box 21066 Charlotte, NC 28277

Circle # 247

RESPOND

Nail-Patella Syndrome

C.M.T. (April 1994) has a son with full-blown Nail-Patella (N-P) syndrome, an easily-diagnosed but rare genetic condition characterized by nail dysplasia, bone deformities and sometime., kidney failure. Ian's parents were looking for up-to-date information on N-P and hoped to hear from another individual or family with the syndrome.

I am 30 years old and have N-P syndrome. I have only the thumbnail involvement and have lived a busy, athletic life.

I have two children. My second was born with excessive tibial torsion caused by the lack of a patella in his right leg and a small, distal patella in his left leg. He wore casts for six and a half weeks after birth, and a Dennis-Brown bar for 14 months after that. He is 30 months old now and walks with a slight limp, but is otherwise happy and healthy.

We have spent four to five hours with a geneticist learning more about N-P syndrome. We learned that N-P syndrome is caused by a dominant gene that is passed on by an affected parent. A person with the syndrome has a 50 percent chance of passing it on. N-P syndrome may be expressed slightly, moderately or severely.

My immediate family is a good example of the various ways the syndrome may be expressed. My grandmother has thumbnail and first-fingernail involvement with elbow dysplasia. My mother has thumbnail and first-fingernail involvement, elbow dysplasia, 56 percent scoliosis and a small/square patella. I have thumbnail involvement only. My sister Barbara has thumbnail involvement, elbow dysplasia and six percent scoliosis. My sister Joan has thumbnail involvement, elbow dysplasia, eight percent scoliosis and small kneecaps. I have three other siblings who do not have N-P and, therefore, can't pass it on.

My grandmother, who came over from Ireland, remembers that her mother had N-P, but she doesn't know who had it in previous generations. Since my extended family has 16 affected members, doctors at Johns Hopkins University are collecting blood from affected and non-affected family members for a study. They already know that the gene for N-P syndrome is on chromosome nine but are hoping to pin down the exact location.

M.K.L., California

Rhizotomy

C.S. (May 1994) has a three-year-old daughter with spastic quadriplegic cerebral palsy. She is non-ambulatory and does not crawl. She has poor trunk control but can sit unsupported on the floor in a ring-sitting position. Her doctor has recommended rhizotomy surgery. Before making a decision, C.S. wanted to hear from parents of similar children who have had this surgery.

My daughter, Leah, sounds a lot like your daughter. Leah had rhizotomy surgery six months ago.

The surgery helped Leah in several ways. It greatly reduced the spasticity in her legs, and it reduced the spasticity in her arms to a lesser degree. Now, she is more comfortable and seems more confident and sociable. We've also noticed that her speech is more fluent, and her articulation is better.

Proving good looks, convenience and proper positioning work wonderfully together.

kid-EZ Adjustable High Chair Base

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle # 46

631

Before the surgery, my expectations were too high. I'd spoken to only one other parent whose child had undergone rhizotomy surgery. Two months later, her kid was practically doing laps, playing the piano and reciting the Gettysburg Address!

Needless to say, our results have not been so dramatic; however, it has been only six months since the surgery. I've heard it is a one-to-two-year process in most cases. At least, Leah no longer has to fight the spasticity day and night. It has improved the quality of her life.

Was the surgery a hassle? Yes. A nightmare? Pretty much. Would I do it again? Yes. But I'm glad I don't have to.

C.M., New York

☐ Your child's condition is very similar to my son's at the same age. Kenny also has spastic quadriplegic cerebral palsy. At 30 months, his only means of mobility was combat crawling. He could not sit or stand unsupported. Fine-motor skills were delayed in his right hand and nonexistent in his left.

The doctors cautioned that following rhizotomy surgery, the typical child regresses. They told us it might be a year before any improvement would be seen. That was not true for Kenny. He had the rhizotomy surgery on his third birthday. The stiffness in his body was gone almost immediately.

Following the surgery, Kenny went to physical therapy five days a week for almost a year. Within months after the surgery, he could sit unsupported, crawl and walk short distances with a walker. Later, he learned to stand unsupported. His fine motor skills also improved. Doctors tell us that his gains are among the best they have seen.

I was apprehensive about putting Kenny and us through the surgery. It required a great commitment from his family and his school. The costs—and not just the financial costs—were great, however the benefits have been priceless. I have known the families of a few other children with cerebral palsy who have had rhizotomy surgery; none have regretted it. Not every child will benefit from the surgery as much as Kenny, but I recommend you give it serious consideration.

C.G., Michigan

☐ Our 11-year-old son also has spastic quadriplegic cerebral palsy. A few years ago, we also were seriously considering rhizotomy surgery for him. Brian sits cross-legged, uses a walker, crawls and transfers almost independently.

We first went to a children's hospital where we met with a neurologist and a physical therapist. Just from watching Brian walk down the hallway without his braces, they immediately determined he was a good candidate for the surgery. They told us they wanted to do it as soon as possible.

We felt uneasy with the speed of their decision and the urgency they conveyed, so we decided to get a second opinion at a different hospital. Brian spent three days there. His evaluations included a gait lab and in-depth evaluations by physical and occupational therapists. Following these evaluations, Brian's case was discussed by a team of doctors and therapists. The team concluded that a rhizotomy was inappropriate for Brian because of the weakness in his trunk. They determined that the surgery would leave him unable to crawl, sit cross-legged and transfer; it might also interfere with his use of a walker. They left the final decision up to us; we felt very strongly that we could not take the chance that Brian would lose some of his function.

I'm telling you our experience only because I want you to make sure your daughter is evaluated very carefully by a team of professionals who have had extensive experience. Once the surgery is done, there is no reversing it. Whatever your decision, we wish you luck.

L.F., Iowa

Bilateral Aniridia

S.G. (May 1994) is the mother of 21-month-old Katie, who was born with bilateral aniridia, a rare condition involving absence of the iris. Katie's diagnosis includes foveal and macular hypoplasia, optic nerve hypoplasia, nystagmus, congenital cataracts, hyperopia, strabismus and amblyopia. Genetic screening has shown that Katie's chromosomes are normal.

S.G. was interested in contacting families of children with aniridia who have had cataract surgery or experience with intraocular or contact lenses with a painted, fixed iris. S.G. also wanted to locate people with aniridia or other eye abnormalities in which there was a history of penicillin or penicillin derivatives being used during the first 10 weeks of pregnancy.

My daughter, Lauren, also has aniridia. Like Katie, Lauren has foveal and macular hypoplasia, nystagmus and strabismus. Her visual acuity is about 20/160 in her better eye and 20/200 in her weaker.

You asked if anyone has had experience using contact lenses with a painted iris—we have. Lauren was fitted with soft, extended-wear lenses at the age of three months. It was extremely difficult to change the lenses for cleaning. A three-month-old does not stay still long enough! Our family had a system, but it was not fun. When it was time to change her lenses, our son laid across her legs with a pillow so she could not kick. My husband held her arms over her head to help keep the head steady, and I took out the lenses. When her lenses were clean, we repeated this process to put them back in. Lauren fought it all the way! She also got a lot of eye infections. We finally gave up on the lenses when Lauren was about nine months old. By that time, she had learned to rub her eyes in a certain way and pop the lenses out. I'll never forget the day she ate one!

Lauren had strabismus surgeries at 18 and 24 months of age. They were very successful. Not only did they give her eyes a more normal appearance, but they seemed to greatly reduce the broad swings of her nystagmus. Her surgeries were uneventful, even easy.

I would like to tell you about Lauren now. She is fully mainstreamed in our local schools. She sees a vision resource teacher twice a week. She has reading glasses and all kinds of magnifying glasses. She maintains a low-B average in a very competitive school.

We are very proud of Lauren's ability in sports. Two years ago, she was ranked sixth in the state in swimming (50-meter freestyle); she has also set many cross-country and track records. This past spring she joined a local softball league; she turned out to be a good batter and second baseman. This summer, she taught swimming at a local day camp. Not too bad for a "blind kid."

Lauren has lots of friends and is forever talking on the phone. Her room is papered with posters of rock stars. She is just like any other teenage girl. We are very proud of her.

R.R., Illinois

632

YOU **NOW** CAN GET A COPY OF THE MAGAZINE THAT HELPS YOU PARENT YOUR CHILD WITH A DISABILITY

12 TIMES A YEAR!!!

THAT'S RIGHT, **EXCEPTIONAL PARENT** MAGAZINE WILL BRING YOU THE INFORMATION YOU WANT AND NEED MONTHLY!

LOOK FOR OUR NEW DEPARTMENTS:

- FATHERS' VOICES
- ROLE MODELS
- ASK THE DOCTOR
- RESEARCH

EXCEPTIONAL PARENT 12 TIMES A YEAR!!!

Yes, I want to subscribe to Exceptional Parent magazine!

❑ One Year (12 issues) for $24*.
❑ 3 Years (36 issues) for $54*. **BEST BUY!**

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

❑ Bill me

❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

_____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34J1

EXCEPTIONAL PARENT 12 TIMES A YEAR!!!

Yes, I want to subscribe to Exceptional Parent magazine!

❑ One Year (12 issues) for $24*.
❑ 3 Years (36 issues) for $54*. **BEST BUY!**

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

❑ Bill me

❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

_____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34J1

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

YOU **NOW** CAN GET
A COPY OF THE
MAGAZINE THAT HELPS
YOU PARENT YOUR
CHILD WITH A
DISABILITY
12 TIMES A YEAR!!!

THAT'S RIGHT,
EXCEPTIONAL PARENT
MAGAZINE WILL BRING
YOU THE INFORMATION
YOU WANT AND NEED
MONTHLY!

LOOK FOR OUR NEW DEPARTMENTS:

- FATHERS' VOICES
- ROLE MODELS
- ASK THE DOCTOR
- RESEARCH

See reverse side for subscription details

RESPOND

☐ We have a 13-year-old daughter, Caroline, who has aniridia. Caroline has the chromosomal abnormality associated with aniridia—a deletion of 11p13-. My understanding is that the deletion may be quite small and may require DNA probe studies to find, but if a person has aniridia, the deletion is there.

We were told about the possibility of Wilm's tumor. We put Caroline on a schedule of ultrasounds every six weeks, and an IVP (x-ray of the kidneys with dye contrast injected) every six months. Some doctors felt this schedule was excessive, but in our case it worked well. Caroline developed the tumor in her left kidney at 18 months. She had the kidney removed and underwent chemotherapy for a year. Since then, she's had no recurrence. We have been told that Wilm's is a risk for our kids until about age five, but it is uncommon after age three and virtually never occurs after age eight.

Caroline's vision is about 20/200 in both eyes. She reads large print and gets around very well. She has nystagmus, macular hypoplasia and bilateral cataracts. Her intraocular pressures have always been normal, but I understand that it is unusual for children with aniridia to develop glaucoma before their late teens.

You asked about maternal exposure to penicillin. I didn't take any antibiotics during my pregnancy with Caroline, but penicillin and its derivatives are among the most widely-prescribed drugs in the world. Most antibiotics are considered safe during pregnancy, and millions of pregnant women have taken them. If there was a relationship between penicillin and aniridia, aniridia would not be so rare.

Having said that, I fully understand your need to find a "reason." I spent a great deal of time searching for one myself. During my pregnancy, I was obsessed with doing everything "right." I ate the most nutritious foods, avoided all drugs and chemicals, exercised, rested and drove everyone around me crazy. But I still gave birth to a child with a birth defect. Why? I still do not have an answer.

You did not mention whether Katie is your only child. I hesitated to have another, but my urge to have another child became overwhelming. Laura is five months old, "normal" and the joy of the entire family.

K.T., Colorado

Skeletal Anomalies

D.D. (June 1994) has a three-year-old daughter, Amanda, with skeletal anomalies. Three of the fingers on Amanda's right hand are webbed; two will be surgically separated. Amanda's legs are normal to the knees, but from each knee extends a three-toed foot with the sole turned inward. Doctors' recommendations have included splinting, partial amputation with prosthesis use and other surgeries. D.D. was looking for other families that have faced similar choices.

I am an adult with skeletal anomalies similar to your daughter's. I, too, have three malformed fingers on my right hand. My right arm is much smaller than my normal left arm and hand. My right leg has what is medically termed a "congenital deficit of the right femur." My pelvis is also malformed. Basically, I was born with a knee which started at the pelvis. My lower leg was attached to the knee and had a normal foot.

My parents did not know how to deal with my skeletal anomalies. Finally, on the advice of a very wise doctor, my right foot was amputated when I was 14 years old. Following the surgery, I was given a fairly well-fitting prosthesis. (Prosthesis design has improved greatly since the first one I received.) My only regret is that the amputation did not take place at an earlier age. That would have allowed me more growing years to have developed skill in using my prosthesis.

At my request, I have not had any surgery to my hand. I can use the hand well and do not care to change what works. There were early attempts at different types of braces, prostheses and assistive devices. All were failures. They just caused pain and more medical problems.

As an adult, I became an occupational therapist. I work in pediatrics. I am married and the mother of five grown children. My husband and I are looking forward to the birth of our fourteenth grandchild in a few weeks.

I suggest that you seriously consider the possibility of amputation and a well-fitted prosthesis, if that option is open to Amanda. Be sure to involve a good prosthetic and research center in developing the best prosthesis for Amanda.

F.M.L., Arizona

Now he has a place for everything like everyone else.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

1-800-4-MYDESC

RHAMDEC

Rhamdec, Inc. • 176 Ellis Street, Mountain View, CA 94043-2240
MYDESC is a trademark of Rhamdec, Inc.

Circle # 103

* Improves coordination, postural control and muscle tone.
* Provides independence.
* Secured in center with belt or seat.
* Trade-in policy.
* S.M.L.
* Covered by most insurance companies.

THE WATER WALKER

* Prone or supine support.
* Contour lines that allow use of arms and legs.
* Straps to secure person on float.
* Pillow for head support.
* S.M.L.

AQUATIC THERAPY FLOAT

Contact:

AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

VISA MasterCard

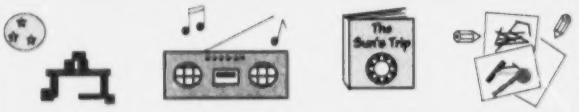
Circle # 170

It Takes Two To Talk

A Parent's Guide To Helping Children Communicate

by Ayala Manolson, M.Sc., CCC

Help your child learn to talk during everyday routines and activities!



GAMES ◆ MUSIC ◆ BOOKS ◆ ART

A beautifully illustrated, user-friendly guidebook for parents of children with language delays. Written by a speech-language pathologist, it contains practical information on how to facilitate communication and language learning within everyday conversations, routines and activities. Used by speech-language pathologists, parents and educators around the world! 151 pages. 1992 edition. $32 (includes shipping and handling).

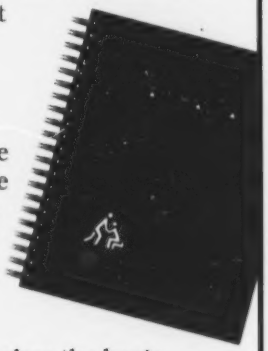
The Hanen Program®

To order, or for a free catalogue, call:
1-800-828-1376 ~ Imaginart, Dept EPM,
307 Arizona St, Bisbee, AZ 85603

Circle # 41

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California



"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 66

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
(609) 346-3300 • FAX (609) 435-4223
Brochure or video available upon request.

"Accreditation with Commendation"
Joint Commission on Accreditation of Hospital Organizations
Member: National Association of Children's Hospitals and Related Institutions

636

Circle # 85

FAMILIAR FACES

*Eight-year-old **Russell Carter** is delighted to get a big hug and kiss from five-year-old sister **Rosey**. Russell and Rosey live in Mint Hill, North Carolina. Russell has cerebral palsy.*

***Gregory Kornacki** loves to wear hats, but in a pinch, the lid from his crayon box works just as well. Greg has spina bifida and is 22 months old. He lives in Northville, Michigan with parents Ed and Nancy, big brother Brian, 5, and twin brother Keith.*

*Four-and-a-half-year-old **Timothy Carl Hammaker** of Port Trevorton, Pennsylvania shares the easy chair with two-month-old brother **Ryan Patrick**. Timmy has VACTERL syndrome, and has undergone 13 surgeries and two heart catherizations. Timmy attends an integrated preschool program. Timmy's mother, Kelly, supervises the early intervention program in two Pennsylvania counties.*

*Just five days after brain surgery, 10-year-old **Laura Giles** was feeling well enough to meet musical trio Peter, Paul and Mary at a local record store. Laura, who has syringomyelia and scoliosis, is entering fifth grade at Roosevelt Elementary School in Poca City, Oklahoma.*

***Hannah Beth Williams'** love of blackberries is written all over her face. Fifteen-month-old Hannah, who lives in Garber, Oklahoma, "doesn't slow down for much," according to mom Peggy. Whenever Grandpa Glen has work to do in the garden, Hannah is right there beside him. Of course, when it comes to blackberries, she eats all she picks.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

637

ASK THE DOCTOR

by David Hirsch, M.D

Respiratory Problems

Q Our daughter is six years old. She has cerebral palsy. In the last two years, she has had many bouts of pneumonia and bronchitis requiring hospitalization and respiratory treatments at home. Her doctors feel she is having increasing difficulty swallowing her food and even her saliva properly. They also feel she may be having gastroesophageal reflux and aspiration. Is there anything we can do to prevent more of these complications?

A Many children with disabilities, especially those disabilities which are moderate to severe, are more prone to respiratory problems (as well as other medical problems). Respiratory problems alone are at least twice as likely in children with moderate to severe disabilities.

There are several reasons for this:

- **Inadequate cough:** Children with neurological or neuromuscular disorders may have difficulty coughing adequately. An adequate cough is one where the child can cough up phlegm (lower respiratory secretions) when the phlegm is blocking some of the lower airway passages. If this blockage persists, the child will have a greater possibility of developing bronchitis, bronchospasm (wheezing) and pneumonia.
- **Aspiration of stomach contents:** Children with moderate-to-severe cerebral palsy and neuromuscular disorders who have abnormalities of gastrointestinal function such as gastroesophageal reflux (abnormal backflow of stomach contents into the esophagus) or dysphagia (swallowing disorders) are more prone to aspiration (breathing in) of stomach contents. This, too, may lead to bronchospasm and pneumonia
- **Swallowing disorders:** Aspiration of injurious material from the mouth, such as saliva contaminated by infected teeth, is more likely if the child has a swallowing disorder. This may lead to pneumonia and other respiratory complications. Good oral hygiene and regular dental visits will lessen the possibility of aspiration of infected saliva.

Parents should be careful to avoid positions and manipulations (such as chest percussion with the head lower than the chest) where aspiration of saliva or stomach contents may be more likely to occur.

- **Aerophagia:** Behavioral problems which cause aerophagia (excessive swallowing of air) may increase pressure in the stomach. This can make reflux and aspiration more likely.
- **Compromised immune response:** Individuals with severe physical disabilities often appear to be less able to "fight off" infections. This may be related to the long-term effects of the illness or disability such as anemia or fatigue. Lack of adequate nutrition and the long-term effects of certain medications may also impair a child's immune response.

After consulting with your daughter's doctor, there are some actions you can take to help prevent some of her more severe respiratory infections.

Use preventative measures to help prevent accumulation of secretions and mucus in your daughter's lungs. Preventative measures may include regular use of small-volume nebulization (inhalation) treatments using medications prescribed by your daughter's physician. Your daughter's physician may also prescribe chest percussions (striking the chest in a non-painful but organized manner to facilitate the loosening of phlegm). These treatments may help your daughter have a more productive cough, too.

Certain studies may be needed to determine if your daughter has gastroesophageal reflux. If reflux is occurring, especially with aspiration, your daughter's physician will recommend corrective measures to prevent further complications.

As noted above, good dental hygiene is important, too. Optimizing your daughter's nutritional status will also help in the prevention of some infections and will improve her overall ability to "fight off" respiratory infections.

***Ask the Doctor** is a regular department of EXCEPTIONAL PARENT in which questions from readers are answered by David Hirsch, M.D., a board-certified pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Whenever possible, Dr. Hirsch makes specific suggestions. However, since Dr. Hirsch is responding to letters and will not have personally examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch occasionally mentions specific products or medications, he is doing so to illustrate his suggestions; he is not endorsing any specific products.

*To submit a question to Dr. Hirsch, write or fax: **Ask the Doctor,** EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

638

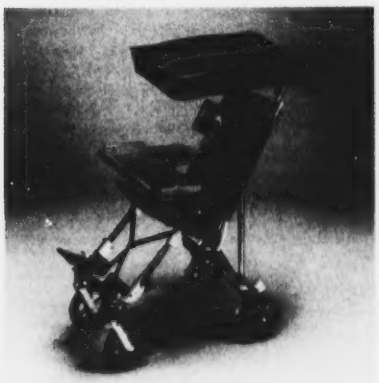
PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

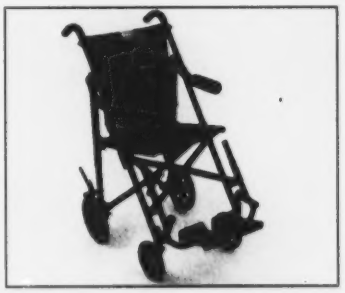
Full Range of Accessories

A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.



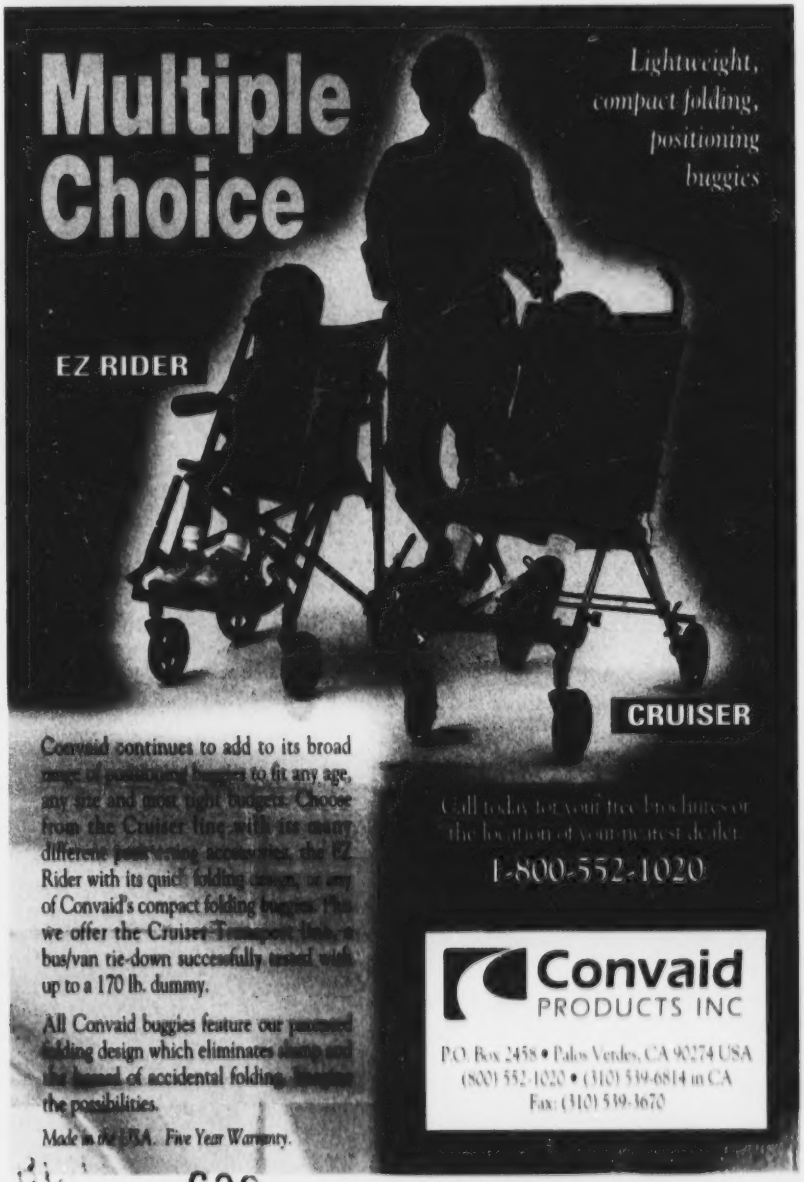
New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.



Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.


Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad
Call today for your free brochures or the location of your nearest dealer
1-800-552-1020
Convaid
PRODUCTS INC
P.O. Box 2458 • Palos Verdes, CA 90274 USA
(800) 552-1020 • (310) 539-6814 in CA
Fax: (310) 539-3670

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

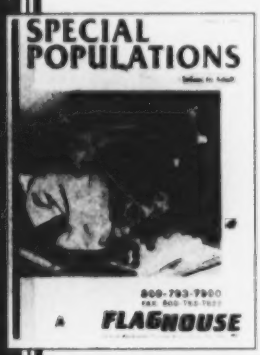
equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

FREE CATALOG OFFER

SPECIAL PRODUCTS FOR SPECIAL PEOPLE



Over 4,000 Quality Therapeutic and Recreation Products

- Manipulatives/Positioning
- Living Aids/Ride-Ons
- Balance Equipment/Mats
- Aquatic Aids/Sports Equipment
- Adapted Furniture/ Toys/Games
- PLUS... a special section featuring SNOEZELEN... sensory stimulation products in a positive, structured environment

Prompt Delivery! Fully Guaranteed!
Low Cost Shipping!

FLAGHOUSE INC.

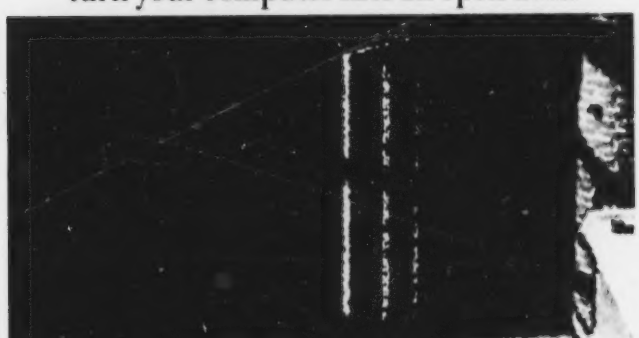
150 No. MacQuesten Pkwy., Suite 96115, Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

Circle # 29

For people with disabilities,

WE CAN

turn your computer into an open door.



A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3383 (TDD); in Canada, 1-800-465-7999.

At IBM, we can do more than you think.

IBM INDEPENDENCE SERIES

© IBM Corp. 1994. ® IBM and Independence Series are registered trademarks of International Business Machines Corporation.

Circle # 121

At The Hospital for Sick Children, excellence has many looks. It is a nurse commanding all her expertise to keep a newborn stabilized. It is a therapist focusing intently on the special needs of a child in the hydrotherapy pool. It is the radiant joy on parents' faces when they take their child home.

Pediatric Nurse Practitioner

We are currently seeking an experienced Pediatric Nurse Practitioner to help develop and manage a program for medically stable preterm infants with residual BPD, apnea, bradycardia, feeding problems, etc. Strong emphasis on infant neurodevelopmental issues, parent training and discharge planning is essential. Current DC licensure required.

The Hospital for Sick Children's mission to be a center of excellence for pediatric rehabilitation and transitional care in the Washington, D.C. area and Mid-Atlantic region is the foundation of all we do. We'd like you to be a part of it, too. For more information regarding our comprehensive salary and benefits package, please call **(202)635-6162** or send your resume to **Human Resources Dept., Attn: Joe Bergman, The Hospital for Sick Children, 1731 Bunker Hill Rd., N.E., Washington, D.C. 20017.**

THE HOSPITAL FOR SICK CHILDREN

An Equal Opportunity Employer.
Residents of D.C. are encouraged to apply.

Circle # 250

At Devereux...

a helping hand is just a phone call away

1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:

- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Locations: Arizona, California, Connecticut, Delaware, District of Columbia, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Tennessee, Texas

For information and assistance, contact National Referral Services 1-800-345-1292

Devereux

Since 1912

Circle #19

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Finding Your Way Through the Medicaid Maze

Medicaid often serves as the primary health insurer for children with disabilities. While the Medicaid program offers some important benefits, it is complex and can be difficult to understand.

These problems have to do with the way in which Medicaid was established and developed. Most industrialized nations offer universal health care, administered by the government and supported by tax dollars. Usually, these countries have clear rules regarding coverage so there is no confusion about what will be covered.

However, the American health insurance system is fragmented and confusing. There's an enormous web of individual- and group-health insurance programs, managed-care plans, health maintenance organizations (HMOs) and state and federal insurance programs.

Established in 1965, Medicaid was intended to provide insurance for families whose income was below the poverty level and for people with severe disabilities. Run primarily through state agencies, Medicaid provides a core of basic services—including doctor visits and hospital care—that's provided in all states, in accordance with federal regulations. However, optional portions of the program may be offered by different states. As a result, Medicaid rules differ substantially from state to state.

Furthermore, some states have been granted "waivers" in regard to specific federal program rules. Such waivers are issued at the request of a specific state's Medicaid program. Once a waiver has been granted to one state, other states may apply for it as well, but they are not obligated to do so.

One waiver that's been granted to several states allows Medicaid funds to be used to pay for at-home treatment for a child with a disability where hospital-based treatment is excessively expensive. This waiver was first granted in the early 1980s, and may apply in certain cases even where the family's income is above the usual Medicaid guidelines.

A more recent waiver deals with rehabilitation programs for children or adults who have experienced severe head injuries. This "head injury waiver" permits Medicaid funds to be used for community-based rehabilitation programs, in addition to the more traditional in-patient programs.

Lawmakers have changed Medicaid over the years. One such change established the Early Periodic Screening, Diagnosis and Treatment (EPSDT) program. EPSDT provides for a periodic medical screening program for children with disabilities enrolled in Medicaid. Medical needs identified as a result of the screening program should generally be covered by Medicaid, even if they would not ordinarily be covered for adults under general Medicaid rules.

Regulations that govern EPSDT are complicated and may be subject to different interpretations, but the program remains a major key to obtaining services for children with disabilities. The very technical *EPSDT Reference Law Manual* is available for $25 through the National Health Law Project at (310) 204-6010.

It is important for parents to know where to turn for help when a Medicaid claim for their child is denied. Most people need help to win an appeal.

One source of assistance is your local legal services office which can offer information and legal representation. Every state has such an office, though it's called by different names in different areas. To locate the nearest office, call the National Legal Aid and Defense Association (NLADA) at (202) 452-0620. NLADA provides phone numbers and publishes a national directory of legal services offices.

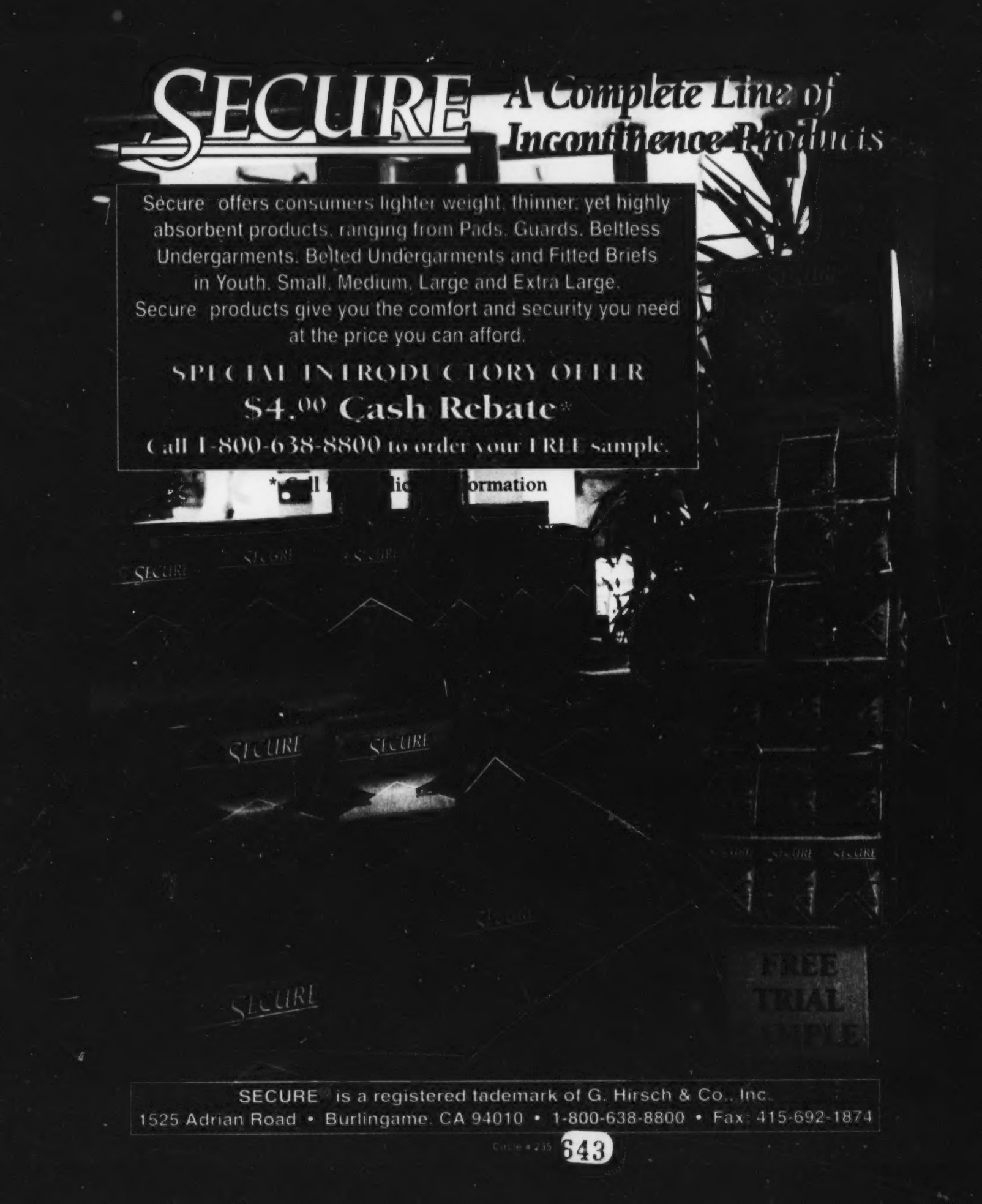
Your local bar association is another source of information. In addition to providing the phone number for the local legal services office, the bar association may be able to refer you to your local protection and advocacy office. The protection and advocacy office may be able to offer help in appealing a Medicaid claim denial. You can also find your local protection and advocacy office by calling the National Association of Protection and Advocacy Systems at (202) 408-9514.

If a Medicaid claim is denied because a specific medical service or piece of equipment is excluded from

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, *209 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742.*

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To insure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.

642


SECURE
A Complete Line of Incontinence Products
Secure offers consumers lighter weight, thinner, yet highly absorbent products, ranging from Pads, Guards, Beltless Undergarments, Belted Undergarments and Fitted Briefs in Youth, Small, Medium, Large and Extra Large.
Secure products give you the comfort and security you need at the price you can afford.
SPECIAL INTRODUCTORY OFFER
$4.00 Cash Rebate*
Call 1-800-638-8800 to order your FREE sample.
ormation
SECURE
FREE
TRIAL

SECURE® is a registered tademark of G. Hirsch & Co., Inc.
1525 Adrian Road • Burlingame, CA 94010 • 1-800-638-8800 • Fax: 415-692-1874

Circle # 235

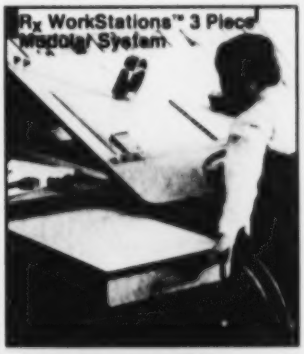
coverage under your state's Medicaid regulations, legislators, support groups and disability rights organizations may also help. Legislators can propose new laws to change the rules under which Medicaid operates. Support groups or disability rights organizations can work with state and federal Medicaid officials to develop an application for a waiver so Medicaid funds can be used to provide services or equipment that are not covered at present.

While the Medicaid system is complex, it can be changed and improved by appealing inappropriate claim denials, and by working with support groups, disability rights organizations, Medicaid officials and legislative leaders. I think that process is essential in helping to clarify current Medicaid regulations and in helping Medicaid to better meet the needs of children with disabilities.

The federal government publishes the 1,000-page *Medicaid Source Book* which provides a good overview of the Medicaid system. It's available for $34 through the Superintendent of Documents, U.S. Printing Office, Washington, DC 20402. The book's stock number is 052-070-06848-5. The book may also be found at public, university or federal depository libraries.

Your local Parent and Training Information Center may also help you find your way through the Medicaid system. Local numbers are listed in *The Exceptional Parent 1994 Resource Guide* (January 1994).

SEE OUR ***NEW*** AND ***EXPANDED*** CATALOG FOR THESE ITEMS AND MORE



PLEASE ASK CUSTOMER SERVICE ABOUT OUR . . . ☐ Free Catalog with 100 plus products & accessories ☐ Trial Use Program ☐ Lease/Rentals ☐ Factory Outlet Store ☐ One Year Warranty ☐ How To Order Direct or via an Authorized Dealer

Since 1978

Consumer Care Products Inc.
810 N. Water St., P.O. Box 684
Sheboygan, WI 53082-0684
Tel: 414-459-8353 FAX: 414-459-9070

Circle # 109

Richer Life **FLEXACISER**

PERFECT SOLUTION
- Multiple Sclerosis
- Stroke-Head Injury
- Spinal Injury
- Cerebral Palsy
- Muscular Dystrophy

HELPS ELIMINATE
- Poor Circulation
- Spasticity
- Muscle Atrophy
- Swelling Ankles
- Stiff Joints

High Quality Electric Motor with Speed Control

(800) 869-0862 • (310) 693-6372

Richer Life, 8131 Allport Ave., Santa Fe Springs, CA 90670

Circle # 214

When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472 . Sometimes your last resort can be the best solution.

C U M B E R L A N D

P.O. Box 150, New Kent, Virginia 23124

645

Circle #18

Additional Sizes Immediately Available!

MIC-KEY®

Skin Level Gastrostomy Feeding Kit

Features . . .

- Designed for improved cosmetic image
- Designed for easy placement and exchange
- Complete size range for Adults and Pediatric patients
- No obturator needed
- Available with:
  - Patented SECUR-LOCK® Extension Set
    - that virtually eliminates disconnects
    - with separate feeding and medication ports
  - Bolus feeding set for easy bolus feeding
- Superior balloon design
  - SHUR-FORM® balloon system assures proper inflation.
- Stoma measuring device
  - Easy to read
  - Provides consistent, accurate measurements.
- Made of clear medical grade silicone material

MEDICAL INNOVATIONS CORPORATION
A DIVISION OF BALLARD MEDICAL PRODUCTS

Ballard Medical Products
12050 South Lone Peak Parkway, Draper, Utah
(801) 572-6800 • Fax: (801) 572-6999

For More Information Call: 1-(800)-528-5591

U.S. Patent Nos. 4,769,592 • 4,886,501 • 4,701,163
Other U.S. patents pending and foreign patents issued and pending

Circle #167

Abraham Nemeth

His parents taught him he could do whatever he wanted—he just had to think of a way to do it

Dr. Abraham Nemeth has led a long and interesting life—one that is difficult to condense to a few magazine pages. Nemeth, who was born blind, became a renowned scholar of mathematics—a field once considered too difficult for people without usable vision. Creator of the Nemeth code for Braille mathematics, he was a professor of mathematics for 30 years at the University of Detroit. He retired in 1985.

"Retired" is a relative term, however, and Nemeth has remained very active. He serves on the Research and Development Committee of the National Federation of the Blind, through which he has developed a talking scientific calculator. Currently, he is working to upgrade this calculator by making it programmable. He recently completed a two-year term as chairman of the Michigan Commission for the Blind.

I was born in 1918 on the Lower East Side of Manhattan. I grew up in a very close and loving family. My parents were immigrants and lacked formal education. They knew nothing about blindness, but had an innate understanding of what was necessary to raise a blind child.

Without realizing it, my father taught me what today would be called mobility and orientation. Whenever we were out walking, he would describe the landmarks we were passing and say things like "Now, we are walking west, and when we make a left turn, we will be walking south. Listen to the traffic. All of it is going in the same direction on this street. But when we get to the next street, you will notice that all the traffic starts traveling in the opposite direction."

My father encouraged me to touch the raised letters on mailboxes, fire hydrants and police and fire call boxes. That's how I learned the letters of the alphabet.

My mother was equally perceptive in dealing with my blindness. When I was very young, she would send me on a trip to the grocery store. She would give me five or six items to memorize, and tell me exactly what to buy and in what quantity. Of course, the grocery store was just around the corner and my grandfather was the grocer. But, I was very diligent in remembering every single item and would bring back everything she had asked for.

My parents also bought me a tricycle. Now remember, I had no sight at all. My father told me that I could ride the tricycle around the block, but that I must remember to make a right turn every time I came to a corner. "Ride slowly," he told me. "Don't bump into anybody, and come back here." That's what I did. I rode my tricycle around the block, and I came back home. One time, my brother, Aaron, and I went on some kind of an expedition. We got separated, and my brother, who had normal vision, got lost; I came home.

[Top] *Ten-year-old "Abie" Nemeth poses with three-year-old sister Marsha in front of his aunt's house in Brighton Beach. Seven-year-old Aaron sits on the steps. Despite the fact that Nemeth had no vision, his mother insisted that he wear glasses "for cosmetic purposes."* [Right] ***Graduation photo:*** *Twelve-and-a-half-year-old Abe graduated from eighth grade in June 1931.*

A curious little fellow

One of my uncles was a handyman. He taught me to thread electrical wire through walls and replace light bulbs. I was fascinated by the way things went together.

This mechanical sense got me in trouble one day, however. In my grandfather's grocery store, he had an icebox which was mounted over a sink. As the ice melted, the water would drain into the sink through a rubber hose. I was a curious little fellow, and one day I went around to the back of the store and discovered

647

this hose trailing to the sink. My mechanical sense told me the end of that hose should be connected to something. So, I felt around and happened upon the faucet. "Aha," I thought, "this hose must belong on the faucet!" I connected the hose to the faucet and left the store, proud of having corrected my grandfather's obvious oversight. A few hours later, I was confronted by my grandfather. I will end the story here.

By 1945, Nemeth was married, but unable to get a job in the field of psychology. His wife finally convinced him he would be happier as an unemployed mathematician than an unemployed psychologist.

Learning to fend for myself

My father did not overprotect me. You know, kids will tease a blind kid. They would get after me, and I would yell, "Pa, he hit me."

My father would ask, "So, why didn't he hit me?"

He was trying to teach me to fend for myself. One time, in the park, a sighted kid was teasing me. When I ran after him, he shimmied up a ladder on the jungle gym. I followed him. He wanted to get out of my way, so he grabbed the highest bar and swung over to the right. He ended up dangling above the ground some distance from the ladder. I climbed back down, but he got so scared that he was unable to move. After that, he left me alone.

An integrated education

I was lucky to have had an integrated education. The New York City public school system provided a resource room for blind children in one school in each of the five boroughs. The one in Manhattan, P.S. 110, was within walking distance of my home. Some kids in the resource room had no sight; some had a lot of sight—but everyone learned Braille.

I went to my regular classroom for academic subjects like arithmetic, geography and history. I went to the resource room when the other kids were doing subjects like penmanship or art. The resource teacher would teach me blindness skills like Braille and typing.

Now, you may not believe this, but I experienced particular difficulty with arithmetic. By the time I graduated from the eighth grade, I had fallen far behind my classmates in mathematics.

In the fall, I entered Evanderchild's High School in the Bronx. This school had a very good resource teacher, who also taught some of the regular math classes at the high school. Upon discovering my deficiency in arithmetic, he immediately took steps to remedy it. In one year, I not only caught up on all the arithmetic skills I should have acquired in elementary school, but I also received top grades in a first-year algebra course. It was during this time that I became keenly aware of an ambition to be a teacher—in particular, I wanted to teach mathematics.

Psychology major

After graduating from high school, I entered Brooklyn College. I wanted to major in mathematics, but my guidance counselors insisted that it was too technical a subject for a blind person, that the notation was too specialized, that volunteer or even paid readers would be difficult to recruit and that I would never get a job in the field. Being compliant, I backed down. In 1940, I graduated with a B.A. in psychology. I had also managed to complete elective courses in analytic geometry, differential and integral calculus, modern geometry and statistics. I continued my education and, in 1942, graduated from Columbia University with an M.A. in psychology.

Better an unemployed mathematician

Despite my years of schooling, I could find only unskilled work. At one time, I worked at a sewing machine, seaming and hemming pillowcases at piece-work rates. I also worked for seven years at the American Foundation for the Blind. There I counted needles for Talking Book phonographs and collated Talking Book records. I loaded and unloaded trucks in the shipping department. I typed letters in Braille, and transcribed incoming Braille letters on the typewriter. I also designed and organized Braille itineraries for Helen Keller, who was an active fund-raiser for the organization. I was fortunate to become well-acquainted with this talented and admirable lady.

After working all day, I relaxed by taking evening mathematics courses at Brooklyn College. By 1946, I had taken all of the undergraduate math courses.

Nemeth reads in his office at the University of Detroit.

That year also brought the end of World War II and the return of many Brooklyn College students. Many veterans had passed first semester calculus before the war and were now returning to face their second semester.

I volunteered to assist those men in reviewing their first semester's work. A large room was set aside for this purpose. All the available walls of that room had blackboards, and each student had a panel of blackboard on which to work. He was instructed to work through as much of a problem as he could, then ask for help. I would ask each student to read his problem from the textbook, and then to read what he had written on the blackboard. Since I had learned to write despite my blindness, I could pick up a piece of chalk to help him complete the solution.

The Nemeth Code

Though I was an undergraduate psychology major, whenever there was an opening for an elective course, I always chose one from the math department. In taking these courses, I found that there was no way of expressing mathematical notation in Braille—just as my counselors had warned. So I began to improvise Braille symbols and methods which were effective for my needs and consistent from one course to the next. By the time I began working toward my Ph.D. in mathematics, I had a code that worked very well. In 1952, my system was published as the Nemeth Code for Braille Mathematics.

The Nemeth Code closely approximates the printed text. This enabled me to communicate with my students as if I were holding the printed text in my hand. Or maybe it was even better than having a textbook in front of me. Before teaching a class, I would put very complicated formulas on cards which I arranged in a small card file in my left jacket pocket. At the right moment, I would casually put my left hand into my pocket to read the formula while writing it on the board with my right. This trick made students believe that I had actually memorized these incredibly complex formulas. It gave them the impression that I was a big genius—and I tried very hard not to disappoint them.

Unbeknownst to me, I was being observed. One Friday, I received a telegram from the department chairman informing me that one of his instructors was ill and would be out for the semester. He asked if I would be willing to assume this man's teaching load. I scrambled to get the textbooks and to prepare a lecture for the following Monday evening. That is how my teaching career began.

By 1951, my wife had convinced me I would be happier as an unemployed mathematician than an unemployed psychologist. She went to work so I could begin my studies toward the Ph.D. in mathematics. In 1955, after a series of part-time teaching jobs, I finally landed a permanent job at the University of Detroit.

A "normal life"

I have led quite a normal life. I think I have been able to do this because I was not overprotected as a child. I had a wonderful support system in the form of relatives, parents and teachers who expected me to do normal things. Because of their high expectations, it never occurred to me that I couldn't do whatever I wanted—I just had to think of a way to do it.

My family gave me opportunities to learn. That's what made it all possible. And that can make things possible for your kids, too. Let your kids participate in household activities and chores. Let them change a light bulb. Let them do the dishes. They will learn if you expect them to do things and if you give them the chance to experiment.

I once had a teacher who told me I was a genius because I was able to read Braille at the rate of a high school student. Now, I don't know what other qualifications I might have for being rated a genius, but reading at the rate of a high school student is certainly not one of them! Expect your kids to do normal things, and then react normally when they do. Encourage them, and do not overprotect them.

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA

Circle # 12

CHARLES C THOMAS • PUBLISHER

☐ Lukken, Miriam W.—**READ THIS BOOK BEFORE YOUR CHILD STARTS SCHOOL.** '94, 240 pp. (7 × 10), 5 il., 1 table, $29.75.

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 284 pp. (6¾ × 9¾), 100 il., 14 tables, $42.75.

☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 308 pp., 13 il., 1 table,59.75.

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $36.75.

☐ Giordano, Gerard—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.

☐ Kluwin, Thomas N. & Michael S. Stinson—**DEAF STUDENTS IN LOCAL PUBLIC HIGH SCHOOLS: Backgrounds, Experiences, and Outcomes.** '93, 174 pp. (7 × 10), 30 il., 10 tables, $38.75.

☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.

☐ Irons-Reavis, Donna—**EDUCATIONAL INTERVENTION FOR THE STUDENT WITH MULTIPLE DISABILITIES.** '92, 140 pp. (7 × 10), 31 il., $30.75.

☐ Lombana, Judy H.—**GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed.** '92, 198 pp. (7 × 10), 1 table, $45.75.

☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.

☐ Reavis, Donna—**ASSESSING STUDENTS WITH MULTIPLE DISABILITIES: Practical Guidelines for Practitioners.** '90, 110 pp. (7 × 10), 13 il., $27.25.

☐ Prickett, Hugh T. & Earlene Duncan—**COPING WITH THE MULTI-HANDICAPPED HEARING IMPAIRED: A Practical Approach.** '88, 90 pp. (7 × 10), 2 tables, $26.50.

☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), $35.75.

☐ Dudley, James R.—**LIVING WITH STIGMA: The Plight of the People Who We Label Mentally Retarded.** '83, 146 pp., 4 tables, $22.00.

☐ Oppenheim, Rosalind C.—**EFFECTIVE TEACHING METHODS FOR AUTISTIC CHILDREN. (2nd Ptg.)** '77, 124 pp., $26.00.

☐ Phillips, Nancy H.—**CHOOSING SCHOOLS AND CHILD CARE OPTIONS: Answering Parents' Questions.** '94, 111 pp. (7 × 10), 5 il.

☐ Love, Harold D. & Freddie W. Litton—**TEACHING READING TO DISABLED AND HANDICAPPED LEARNERS.** '94, 260 pp. (7 × 10), 8 il., 23 tables, $49.75.

☐ Williams, Leslie A. & Lucile S. Arntzen—**A PRACTICAL APPROACH TO RSP: A Handbook for the Resource Specialist Program, 2nd Ed.** '94, 120 pp. (7 × 10), 2 il., 4 tables. $29.75.

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.

☐ Koziol, Leonard F., Chris E. Stout & Douglas H. Ruben—**HANDBOOK OF CHILDHOOD IMPULSE DISORDERS AND ADHD: Theory and Practice.** '93, 252 pp. (7 × 10), 2 il., 18 tables, $53.75.

☐ Adamo-Tumminelli, Pat—**A GUIDE TO PEDIATRIC TRACHEOTOMY CARE. (2nd Ed.)** '93, 90 pp. (8½ × 11), 46 il., $25.75, spiral (paper).

☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.

☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¾ × 9¾), 113 il., 19 tables, $59.75.

☐ Trief, Ellen—**WORKING WITH VISUALLY IMPAIRED YOUNG STUDENTS: A Curriculum Guide for Birth–3 Year Olds.** '92, 230 pp. (7 × 10), 3 il., $41.75.

☐ Jones, Carroll J.—**EVALUATION AND EDUCATIONAL PROGRAMMING OF DEAF-BLIND/SEVERELY MULTIHANDICAPPED STUDENTS: SENSORIMOTOR STAGE.** '88, 314 pp. (7 × 10), 1 il., 67 tables, $59.25.

☐ Blanco, Ralph F. & David F. Bogacki—**PRESCRIPTIONS FOR CHILDREN WITH LEARNING AND ADJUSTMENT PROBLEMS: A Consultant's Desk Reference. (3rd Ed.)** '88, 264 pp. (7 × 10), $33.00.

☐ Durán, Elva—**TEACHING THE MODERATELY AND SEVERELY HANDICAPPED STUDENT AND AUTISTIC ADOLESCENT: With Particular Attention to Bilingual Special Education.** '88, 250 pp. (7 × 10), 5 il., 3 tables, $45.50.

☐ Houts, Arthur C. & Robert M. Liebert—**BEDWETTING: A Guide for Parents and Children.** '84, 110 pp., 9 il., $20.75, paper.

Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice

2600 South First Street Springfield • Illinois • 62794-9265

Circle # 10

The First Day of School

by Janneane Randall

Today is the first day of school. My son, Andy, is entering the first grade. He gets on the bus as if this were any other day. But I know that today is very special. I am excited for him and very nervous. I want him to like his new school and his teachers. I want him to be accepted and to make new friends.

On this first day of school, I have the same hopes as all parents. But my fears are different—as different as my son.

When Andy was very young, my husband and I knew that something was wrong. His language was not developing appropriately, and his behavior was "not quite right." After many evaluations, Andy was diagnosed with autism.

Andy (right) eats lunch at school with his friend, Zach.

Andy spent three years at a wonderful "special" school. He learned to make friends with the children in his class because social skills were a part of every child's IEP. In a world where being the same as everyone else is so important, his school was a safe haven. There, he *was* the same as everyone else. No one stared when he made funny noises or flicked his fingers in front of his eyes. No one thought it strange that he could not communicate like other children his age.

On his last day at that school, I walked him around the classroom to shake hands and say goodbye. Some children wished him luck; others wanted to know if his new school was very big or if he was scared. Each of his teachers gave him big hugs and kisses. Everyone told me how much they would miss him. Some of the teachers cried as they said goodbye. I cried, too.

Today is the first day of school. It is time to move on, time to give inclusion a chance. Other parents who have done this tell me that even though it is not easy, it is the right thing to do. I try to believe this, but there are times when I have my doubts. A good and wise friend tells me that if I wait for Andy to become more normal before sending him to regular school, I will be waiting forever. I know she is right. It is unfair to Andy to keep him sheltered in a special school forever—I know that he will have to face the real world someday. But in my heart, I long to have him back in that safe place.

Andy's sister, Allison, is worried too. She is 10 years old—a self-conscious age when everything is a potential embarrassment. She is afraid the other kids at school will think that her brother is "weird." She worries they will call him names. She worries they will make fun of her, too. I can't promise that her worst fears will not be realized. I tell her if kids tease, it is because they don't know any better. Allison considers that small consolation.

Today is the first day of school. How will Andy cope with this new world? For the first time ever, he will have recess, library time, music class and lunch in a cafeteria. He will be one in a class of 30 instead of eight. When he gets confused or upset, I hope he will not bite his hand and scream "No!" like he does at home. I also know this hope is unrealistic.

Today is the first day of school. I will worry, hope, pray and dream. I want this to work; I want this more than anything I have ever wanted before. I want Andy to be happy. I want him to make a friend. I want people to see him for what he is—another child, just like all the others.

Hard work pays off

Andy's first year in public school was ultimately successful, but it was a success born of great challenges, teamwork and a willingness to try new ideas.

Initially, Andy had a hard time adjusting to this new and often overwhelming environment. He responded by having tantrums and biting himself.

Fortunately, his teachers and the special education director were willing to be creative. Andy's sensory integration therapist came into school to train his teachers and his aide. An inclusion specialist helped everyone work more effectively with Andy, and helped them understand the reasons for his problems.

By mid-year, Andy was doing well in school and seemed happy. He was interacting with the other children, making friends and getting invited to birthday parties.

This past year wasn't an easy one, but we accomplished something important. Andy became the first child with autism to be included in a regular classroom in our town's public schools. Now, second grade is just around the corner. This year, I face the first day of school without the doubts and fears of last fall. Andy has proven that with the proper supports, he can succeed in public school.

Jan and her husband, Bob, live in Seekonk, Massachusetts with Allison, 11, and Andy, who will be nine in October. Jan recently started a support group for mothers of children with autism who live in southeastern Massachusetts and Rhode Island. She works at Community Autism Resources, a public service agency.

651

INCLUSION:
What It Is, What It's Not, and Why It Matters

by Dorothy Kerzner Lipsky and Alan Gartner

Few educational topics have attracted as much recent attention as inclusion. Inclusion has been the subject of news stories, opinion pieces, television specials and heated debate in professional journals. This attention comes in response to pressure from parents and educators to set higher standards and goals for all students. The concept of inclusion is based on the recognition that we live in a society of increasing diversity, where success will come to those who learn how to work and live cooperatively with others. For the parents and families of children with disabilities, the topic of inclusion raises critical questions about quality education for their children.

Inclusion is not...

Inclusion is not "dumping." It does not fail to recognize the reality—and the legal requirement—that each child requires a program designed to meet his or her unique individual needs. It does not benefit some students at the expense of others.

Inclusion is not a new label for "mainstreaming." Mainstreaming was an educational philosophy and practice which assumed the existence of two separate systems—regular education and special education—in which integration was largely limited to non-academic activities.

Inclusion is not a way for school districts to save money. Inclusion does not involve cutting needed services.

Inclusion is...

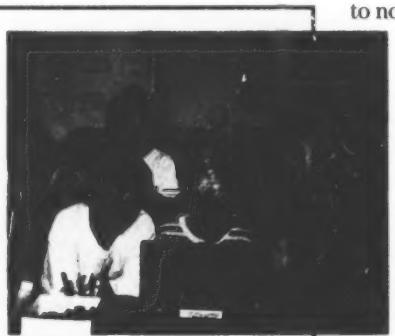
Inclusion is the provision of services to students with disabilities, including those with severe disabilities, in their neighborhood schools, in age-appropriate regular education classes, with the necessary support services and supplementary aids—for both children and teachers. The goal of inclusion is to prepare students to participate as full and contributing members of society. Inclusion means meeting the law's requirement of a "free, appropriate public education" in the "least restrictive environment."

What makes inclusion programs successful?

The National Center on Educational Restructuring and Inclusion (NCERI) recently completed a national study of inclusion programs in urban, suburban and rural locations. The study identified several components of many successful inclusion programs. These include:

Columbine Elementary School
Woodland Park, Colorado

Columbine Elementary School's journey toward inclusion began three years ago when Principal Mike Galvin decided that all children belonged together. Today, there are no segregated classrooms at the Woodland Park, Colorado school. Children with disabilities, in kindergarten through fifth grade, are included in regular education classrooms, in the playground, in the cafeteria and in extracurricular activities.



Benjamin Snow shows classmates how his Apple Powerbook computer works.

Seven-year-old Benjamin Snow, who has cerebral palsy, enjoys classroom activities with his friends. Chris Doyle, 10, a fourth-grader who has cognitive impairments, listens to his books-on-tape while reading along with other students who read silently.

Because of techniques and strategies like teacher training, team teaching, environmental adaptations, assistive technology and positive behavior plans, inclusion at Columbine has been accomplished.

Nominated by Kathie Snow, mother of student.

Chris Doyle gets a "high-five" from classmate Nicole.

652

• **Strong leadership:** Leaders must recognize that students with disabilities can benefit from quality educational programs with their regular education peers—and that students without disabilities will benefit as well. They should have an optimistic view of the capacity of teachers and schools to change and to accommodate the needs of all students.
• **Collaboration:** No single teacher should be expected to have the expertise to meet the educational needs of every student in the classroom. Rather, individual teachers must be given support systems that provide collaborative assistance and enable them to engage in cooperative problem solving.
• **Supports for students:** Supports include everything necessary to enable the child to meet IEP goals and to succeed in a regular classroom. This may include adapted curricula, tutoring, counseling and both in- and out-of-class therapies.
• **Re-focused use of assessment:** Instead of using assessment to document student inadequacies, assessments should focus on what students can do and how educators can help them meet IEP goals and objectives in the regular classroom.
• **Funding:** Funding must be sufficient. Inclusion is not done to save money at the expense of student needs. Preliminary research shows that districts which are implementing inclusion report that it does not cost more over time; rather, costs are shifted.
• **Effective parental and family involvement:** Successful inclusion programs encourage parental participation through family support services, such as support groups and counseling, and the development of educational programs which involve parents and other family members.

> Historically, we have had two educational systems—one for students with disabilities and one for everyone else. We are working to create one educational system that values all students. The regular classroom in the neighborhood school should be the first option for students with disabilities. Administrators and teachers must receive the training and the help they need to make that the best option as well."
>
> —JUDITH HEUMANN
> Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education

Kids Kampus
Huntington, Indiana

Built specifically for children with special needs, Kids Kampus in Huntington, Indiana, also integrates its students with more than 77 three- to five-year-olds without disabilities.

Stephanie Truitt loves going to school.

Five-year-old Stephanie Truitt, who is developmentally delayed, has been attending the school for three years. "Stephanie is age appropriate in most areas and will be attending regular kindergarten in the 1995-96 school year," said Stephanie's mother, Nancy. "She has one more year at Kids Kampus and I dread the day she has to leave."

Children at Kids Kampus benefit from three outdoor playgrounds, an indoor playscape equipped with sand and water tables, bubble balls, riding toys for children with special needs, various climbing equipment and fully equipped therapy rooms.

With field trips and visits to a nearby college for some swimming, the students are also exposed to activities that promote integration into the community.

Parents receive training in areas like sign language and advocacy and receive emotional support as well.

Nominated by Nancy Truitt, mother of student

Your role as a parent

• *Learn about successful inclusion practices* so you can make an informed decision about whether inclusion is the best educational approach for your child.
• *Learn about the law and recent court cases.* Inclusion is not something a child must earn. The school system has a legal obligation to pro-

653

Mountain Sky Junior High
Phoenix, Arizona

Seven severely challenged junior high school students are now integrated in science and government classes at their local school, thanks to staff and parent efforts on their behalf. This past school year, parents and Mountain Sky staff decided on team teaching in regular classes to provide extra assistance for all students. They also created a study hall for added support.

Cooperative learning groups benefit all students.

The response from students and staff has been positive. One staff member commented, "If you want to know who inclusion has helped, it's been the regular kids who are less frightened of people who are different. And they've learned that it's OK to be different."

Nominated by school staff as suggested by a parent of a student

vide an appropriate inclusion program if it is requested. A student cannot be placed in a more restrictive setting unless a school system can demonstrate that inclusion has not been successful despite the school's provision of necessary support services and supplementary aids.

- *Recognize the IEP as a powerful tool* to assure that your child's program provides all necessary support services and supplementary aids.
- *Support schools and districts in developing inclusion programs of quality.* Successful inclusion programs are ones which have been developed carefully, with input from everyone who will be involved—administrators, teachers, families and students.
- *Get involved with local and national parent and family organizations* to assure that schools serve and provide a successful education for all children.

Dorothy Kerzner Lipsky, Ph.D., is Director of the National Center on Educational Restructuring and Inclusion. She is the parent of a 25-year-old son who has spina bifida. Alan Gartner, Ph.D., is Dean for Research of The Graduate School and University Center, The City University of New York. They are co-editors of Beyond Separate Education: Quality Education for All *(Paul H. Brookes, 1989), and co-authors of* Supporting Families With a Child With a Disability: An International Outlook *(Paul H. Brookes, 1991). Both books can be ordered by calling (800) 638-3775.*

A summary of the NCERI report is available at no cost. The full report, which includes a listing of school districts implementing inclusion, is available for $9, prepaid. Write to NCERI, The Graduate School and University Center, The City University of New York, 33 West 42nd St., Room 1530, New York, NY 10036.

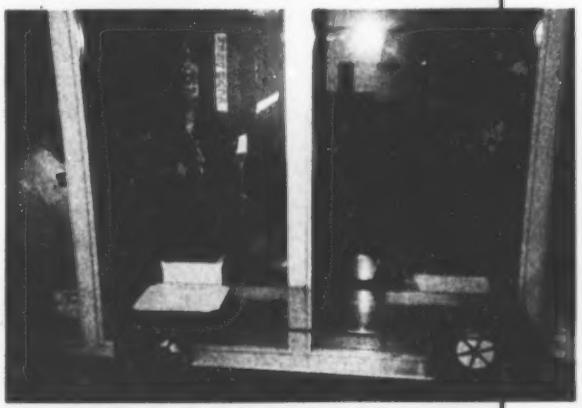
JC Sweeny Kindergarten
Pascoag, Rhode Island

Ann M. Bisson says you can't tell that her eight-year-old daughter, Holly, is any different from the other children in her kindergarten class. Holly, who has Down syndrome, joined a regular class "partly because we knew she could do it and partly because the teacher wanted to have Holly…because her belief is that all kids are kids," Ann says.

Now, Holly is required to do all the work that her peers do. "When the class was tested at mid-year…she came up in the middle of all the kids," her mother notes.

Holly is considered to be one of the gang. "This inclusion is real because you cannot pick Holly out of a crowd of kindergarten kids and because her teachers fight for her rights to be a person," Ann says.

Nominated by Ann M. Bisson, mother of student



Holly Bisson is just one of the gang during a class outing to the local fire station. (She's in the front row, wearing a red shirt and glasses.)

654

EDUCATION

Inclusion and Ideology

by Albert Shanker

The movement in American education that is taking hold the fastest and is likely to have the most profound—and most destructive—effect is not what you might think. It's the rush towards full inclusion of children with disabilities in regular classrooms.

Advocates demand that all children with disabilities be put into regular classrooms, regardless of their ability to function or benefit, and regardless of the effect on other children in the class. And they are being successful. Full inclusion is happening quickly, all over the country, without substantial debate in state legislatures and school boards, through court orders and federal directives.

As a result, we are seeing children who are medically fragile and children with severe behavioral disorders placed in regular classrooms where teachers who have had little if any special training—and get little if any extra help—struggle to deal with the youngsters' special needs. This could mean suctioning mucus from a child's lungs or giving him a medicated enema. Or it could mean trying to figure out how to handle a child who bites and kicks others with no apparent provocation and shouts or cries and exposes himself throughout the school day. All this while the teacher is attempting to give other students the grounding they need in math and reading and science.

Full inclusionists argue that all the supports that children with disabilities have in special education settings must follow them into regular classrooms. This is no more likely to happen for children with disabilities than it did for people with mental illness who were de-institutionalized years ago. Their supports were also supposed to follow them when institutions were closed, but the supports never materialized; now, as we know, many of these people are out on the streets. That's one reason why many parents of children with disabilities oppose full inclusion. They fear their children will lose the range of services now available and end up, like those people who were de-institutionalized, with nothing.

We usually think of schools as performing three functions: imparting knowledge and skills; preparing students for the working world; and helping them become good citizens and develop socially. But those demanding full inclusion are interested in only one thing—socialization. Teaching kids with and without disabilities to get along together is worthwhile (as many schools that don't practice full inclusion would agree), but it is only one value. And it's certainly not the only reason taxpayers support the schools.

Students use electronic communication devices to compose music.

HMS School For Children With Cerebral Palsy

Philadelphia, Pennsylvania

The HMS School for Children With Cerebral Palsy in Philadelphia, Pennsylvania encourages its students to achieve the highest levels of independence and freedom that they can.

For example, the language arts program helps students build their language skills while talking about their feelings, creating stories and writing letters to former classmates.

Parents of children who attend HMS boast of the many opportunities offered to students at the school—assistive technology devices, participation in recreational activities and plays, and a chance to help run the school's convenience store. Many students are given the chance to demonstrate independence by running errands, collecting attendance slips and going to therapy sessions without supervision.

Students participate in a science lesson in preparation for the annual science fair.

The school's medical staff proved to be "lifesaving," according to one mother who called HMS her son's "second family and his home away from home."

Nominated by Carol A. Olinick, Rebecca Little and Marie A. Campagne, mothers of students

Full inclusion is often justified by an analogy with the racial segregation practiced during a good portion of our history. Just as "separate but equal" always meant "inferior," inclusionists feel the same is true of any separate classes for any children with disabilities. But the analogy is faulty. African-American children have the same range of abilities and needs as white children. They were excluded only because of the color of their skin, which was irrelevant to their ability to function in a regular classroom and to benefit from being there. This is quite different from putting a youngster who is blind into a special class so he can learn Braille or excluding a youngster who is emotionally disturbed because he will disrupt the education of the other kids—while deriving little benefit himself.

Recently, I received a letter from Edwin Martin, who was the first director of the U.S. Bureau of Education for the Handicapped and now heads an advocacy group for people with disabilities. He, too, opposes full inclusion, and he is especially troubled by the idea of making sweeping changes without any data or research to support these changes. Where are our figures on how well students with disabilities in regular classrooms do in comparison with those in special education settings? How many drop out? How many go on to college or vocational programs? Without this kind of information, we have no way of knowing what is working for these youngsters and what is not. "Special education programs," Martin says, "must be judged on their successes, not on our wishes for a more inclusive society."

Many children with disabilities can be, and are now, included in regular classrooms and, with adequate supports, many more could be. These decisions should be made on an individual basis—depending on the nature and severity of the disability—and remade if a placement turns out to have been wrong. And these decisions should be based on what is good for all the children involved—the children with disabilities and the others. But full inclusion makes no room for individual judgments. It is an ideological position that children with disabilities and children without disabilities must always be fully integrated, regardless of the circumstances or consequences.

Some full inclusionists talk as though they are in a battle pitting the forces of morality against the forces of immorality. In reality, the battle pits ideologues who, without any evidence, would force destructive changes on our schools against people who believe that children's interests come first.

© Albert Shanker, 1994

Albert Shanker is president of the American Federation of Teachers (AFT), an affiliated union of the AFL-CIO which represents 830,000 education professionals. Shanker's comments appear in THE NEW YORK TIMES every Sunday in a space paid for by the AFT. This column appeared on Feb. 6, 1994.

Wonder. Discovery. Delight.

We cover the basics.

Edmark software does more than teach kids about math, reading and science. Our programs *delight* them—with colorful graphics, children's voices and *lots* of humor. Positive feedback and visual and auditory cues gently guide them to success. Using the optional TouchWindow, they can interact directly with the software simply by touching the screen.

For more information and a free product catalog, call **1-800-320-8380**.

Winner of 40 Awards!

Millie's Math House, Bailey's Book House, Sammy's Science House (PreK–2nd Grade), Thinkin' Things, KidDesk (PreK–5th Grade), and the TouchWindow. Available for Macintosh and IBM/compatibles.

All Edmark software features built-in single switch scanning.

EDMARK

1545a 8/94

Circle # 24

656

EDUCATION

A National Agenda For Achieving Better Results

by Thomas Hehir

When we discuss improving results for children and youth with disabilities, we need to talk about both our successes and our shortcomings. Many children and youth with developmental disabilities are now living in and enjoying community life, but many continue to be segregated in our education system. This needs to be taken very seriously because we know that the degree to which students with disabilities are integrated with their peers without disabilities is critically important to their future success in employment and community living.

Impact of P.L. 94-142

Since the 1975 passage of P.L. 94-142—originally called the Education for All Handicapped Children Act, but later renamed the Individuals with Disabilities Education Act (IDEA)—the institutionalization of people with mental retardation has gone down 63 percent, which is an enormous change in a very short period of time. But for me, a more impressive statistic—although we would like it to be lower still—is that only 1.4 percent of young adults with developmental disabilities in the U.S. are institutionalized. This is a testimony to what we have been doing over the last 19 years.

Prior to the passage of P.L. 94-142, the needs of many children with learning disabilities were not recognized. We now know that results are better for those who receive appropriate support, placements and access.

We know from our research that we have made gains in employment for young adults who have left our educational system. But the rate of employment among adults with disabilities should and could be higher.

Without this legislation, hundreds of thousands of people would be in institutions and the school dropout and unemployment rates among people with disabilities would be much higher.

Although many children are achieving at levels never before thought possible, we still must be very concerned about the 38 percent dropout rate for students with disabilities in this country—almost double the dropout rate for students without disabilities.

On the National Agenda...

• **Integration and Inclusion:** Our longitudinal study shows good results for students who are integrated into regular education classrooms with appropriate supports, aids and accommodations, and with access to the regular-education curriculum. For example, young people with physical impairments who had

Christian Learning Center
Michigan

This past year, the Christian Learning Center provided inclusive education services to about 90 children in seven Christian schools in western Michigan. The system includes a "Circle of Friends" for each child. High school and post-high school age students receive training and follow-along vocational services, which are available in community-based and inclusive work settings.

Last May, the Center held its first Inclusive Games, an event planned and supervised by middle school students. Two hundred children—with and without disabilities—participated in a wheelchair obstacle course, a Nerf arrow shoot, a free throw contest and other games. They competed in teams made up of one child with a disability and two without.

Nominated by Dr. Thomas Hoeksema, Calvin College Education Department

been in regular education full-time, were 43 percent more likely to have a job than those who had been in regular education only half-time.

• **Support services:** Research shows that significant numbers of students with disabilities who have been integrated into regular classrooms receive next to no support from special education. Few receive modification in the way material is presented or in the curriculum itself. Many regular classroom teachers have not received adequate training.

If we redefine special education as services and placements that students need in order to be successful, then we will go a long way toward addressing a lot of concerns that people have. Children with disabilities should be educated in an individualized manner in the least restrictive environment, with appropriate supports, aids and accommodations.

• **Job training and placement:** Although we feel strongly that students with disabilities must have access to all the options that students without disabilities have, it is particularly important to recognize the importance of vocational education. According to our research, students with mild disabilities who received concentrated vocational education that included job placement possibilities, now have a more than $6,200-a-year earnings advantage over students without disabilities who have not had this type of program.

Although vocational programs are not appropriate for all students with disabilities at the secondary level, we should have a good idea of the type of program he or she needs to prepare for the future. We need to take a broad view of the IEP. We need to get away from the myopia of short-term objectives and look at the ultimate results we want to see three or four years from now.

• **Higher education:** It disturbs me that only 13 percent of students in special education go on to higher education. We should be looking at appropriate community colleges and four-year colleges for these students.

• **Earlier interventions:** The later we intervene with students who have reading problems, the poorer their results will be. If we do not intervene with students until the third or the fourth grade, we can almost be sure to have poor results.

• **Problems in minority communities**: Special education is not highly supported in some minority communities. Many students with disabilities in minority communities are placed in dead-end programs with low expectations and are removed from instructional accountability systems.

• **Participation of parents and adults with disabilities**: We need to develop better ways to involve parents. Too often, there is an unfortunate assumption that school districts and parents of students with disabilities are adversaries. Parents should be actively involved in the decision-making process.

It is also important that we recognize that our students with disabilities become adults. For this reason, adults with disabilities should have a say in the education of the children who follow them.

• **Low-incidence disabilities**: We have to pay more attention to low-incidence disabilities. Often, due to the low incidence of certain disabilities, students who are blind, students who are deaf and students who have multiple disabilities do not receive the kind of attention they should from their school systems. In many cases, this seems to be caused by a lack of expertise at the local level.

A Focus on Results

I believe it is important for all of us to take the theme of "a focus on results" very seriously—all of us need to focus on improvement and better results for students with disabilities. Secretary of Education Richard W. Riley frequently uses the expression, "Only the educated are free." As we concentrate more on providing students with better educational opportunities, we can help "free" all children, youth and adults with disabilities in this country.

Thomas Hehir is the director of the Office of Special Education Programs, U.S. Department of Education. This article was adapted from his speech, A National Agenda for Achieving Better Results For Students With Disabilities.

Shipley's Choice Elementary School
Millersville, Maryland

Since 1989, Shipley's Choice Elementary School has included children with disabilities. The school has 490 students, including 29 children with moderate to severe disabilities. Students conduct daily morning announcements that are closed-circuit broadcast to the classrooms and sign interpreted. During the announcements, a student presents the "sign of the day."

The school has an active peer buddy program where students without disabilities are paired with students with disabilities for recess and other occasions. The bond created between the students was evident last February during one of the school's Awareness Week sessions when a fourth-grade student and buddy of a boy with autism raised his hand and said, "My buddy… No, my friend is the best artist I know."

Nominated by Mary C. Barbera, mother of student

Students sing and sign holiday songs.

658

Making Inclusion Work

Angela is supported by a circle of friends.

by Janine Guida, Stephanie Pirsos, Katherine Schempp and Diana Cuthbertson

***ALL CHILDREN BELONG** is an awareness and training program designed to enhance the ability of communities to support the participation of children and youth with disabilities in schools, workplaces and community activities.*

The first phase of the ALL CHILDREN BELONG curriculum is the awareness phase—when parents, educators and community members learn about the basic concepts of inclusion. Key planning activities take place at this time. A hallmark of this second phase is the development of teams that will build on an individual's strengths to find ways to facilitate meaningful participation in activities.

There is no single recipe for inclusion. Each child is unique; each school or community setting is unique. But no attempt at inclusion will succeed without teamwork. The story of how Angela's family, school and community worked together to ensure her successful inclusion offers a compelling illustration of the teamwork required to make inclusion work.

When Angela Hart was born with Down syndrome, her mother, Vicki, resigned herself to being Angela's caregiver-for-life. Now, eight years later, Vicki and her husband, Lynn, envision Angela's future differently. They believe that Angela, as an adult, will be a contributing member of her community.

Much of the change in her parents' perspective has had to do with Angela herself—her sunny personality and many abilities. But they agree that inclusion has played a part as well.

Getting Ready for Inclusion

Merle Soroco, the learning consultant on Angela's multi-disciplinary team, believes that Angela's family played a strong role in preparing her for inclusion. "Vicki took Angela everywhere she went—to the store, to her brothers' sports competitions and to church," Merle comments. "Everyone in the community knew Angela before she entered kindergarten, so no one was surprised to see her."

Angela had some other advantages also. Merle cites Angela's outgoing personality and good language skills. "Angela's language skills helped her to make new friends," Merle says, "but as importantly, her language abilities kept her from becoming frustrated. She was able to communicate her needs."

Building a Team

Angela, her parents and brothers, her regular education and special education teachers, the school principal, related-services providers (occupational, physical and speech therapists) and the multi-disciplinary professionals (social worker, psychologist and learning consultant) are the members of Angela's team. The team plans Angela's goals, learning activities and supports. They also assume cooperative responsibility making accommodations or adaptations in Angela's educational program and for evaluating her progress.

Angela's team meets four times each year. Meetings start with a review of Angela's many accomplishments. Then, any major concerns are addressed. Day-to-day issues are discussed during teachers' planning times and through home-school communication.

Strengths and Needs

Completing a "Positive Student Profile" was one of the first activities Angela's family did to prepare for her inclusion in public school. Angela's parents and older brothers—Bobby, 12, and Tony, 13—wanted the important information they knew about Angela's strengths and interests to be available to the team that would be developing Angela's IEP. In this year's profile, Angela's family describes her as a child who loves school, friends, sports, dancing and the Brownies. Her strengths include a "terrific sense of humor," good manners, an ability to ask for help and an "I do it!" attitude.

Angela, holding a sign that says "Plant A Tree," was one of the "stars" of the class Earth Day play.

The profile also documents Angela's successes at home and school. She knows her address and phone number, uses slang properly and sits through quiet activities. She uses a calculator to compute math problems and does some homework without assistance.

The profile also documents Angela's needs. These include a need to speak more clearly, read independently, learn from peers and adults who can show her how they solve

State of Georgia

In the last two years, the state of Georgia's Council Steering Committee—a group of parents, teachers, administrators and therapists—has funded 13 inclusive education sites across the state. Typical is the Bartow County School System, which began its inclusion program three years ago. Terry Drew, principal of Bartow County's Adairsville Elementary School, said inclusion has been "super successful." The Bartow County system is now listed as an Innovative Special Education Program (ISEP) and is considered a model for other school systems.

One Bartow County student, Brandon, sent a note and kisses to his teacher because he loved being included in her class. The father of Piper, another "included" student, said, "It is very refreshing to find a school system so open and committed to making the appropriate accommodations without turning the process into an adversarial contest as has been our recent experience with Piper's former school."

Bartow's approach, according to Piper's father, is "common-sense, friendly and welcoming."

Nominated by Joyce R. Ringer, family support coordinator for the Governor's Council on Developmental Disabilities

problems and receive support in extracurricular activities. Safety issues are also a high priority for Angela's family. They want her to use care in selecting friends and in traveling in her community. These strengths and needs are kept central to all planning activities.

Honorable Mention

Parkview Montessori School, Mt. Prospect, Illinois
P.S. 279, Brooklyn, New York
Searles Elementary School, Union City, California
E.H. Slaybaugh School, Egg Harbor Township, New Jersey
Center Elementary School, Brookfield, Connecticut
Fairfield Elementary School, Maumee, Ohio
New Vision Dance program at Clarkstown High School South, West Nyack, New York
Beach Channel High School, Rockaway, New York
Weight Conditioning Program at Tren-

Identifying Resources

Before children with disabilities can successfully attend neighborhood schools, it is important to understand the supports which can facilitate participation. A "support" is anything it takes to provide assistance to children with disabilities and all the people working with them.

Angela's supports can be divided into five categories—personnel, environmental, curriculum adaptations, evaluation and peers. Having Angela's teacher complete a "Classroom Activity Analysis Worksheet" helps her team to choose appropriate supports. The worksheet includes a list of daily activities. Some activities require no special adaptations; others require adapted materials and/or assistance from peers, the teachers, a therapist or an aide.

- **Personnel:** Many people contribute to Angela's success. The school's *principal* is very supportive of inclusive education. His leadership sets the tone for the school.

The *classroom teacher* is Angela's most important support. Angela is placed in a relatively small class. She has a *full-time aide*, but the aide is available to any child in the class.

In addition, Angela has a *resource room teacher* and *occupational, physical and speech therapists*. Her therapists do both in-class and pull-out activities with Angela. For example, one of Angela's goals is to be able to speak in public. Her speech therapist taught Angela's class about public speaking and had each of them do an assignment. The resource room teacher works in the regular classroom on specific curricular goals that have been tailored to Angela's needs.

- **Environment:** Angela's classroom is set up to help meet her needs. For example, her teacher chose a "U-shaped" seating arrangement for the classroom. This ensures that Angela will always have a peer supporter on either side.
- **Curriculum:** Angela spent her second-grade year in a classroom with a

Classroom Activity Analysis Worksheet

T=Teacher
A=Aide
P=Peers
RC=Resource Center
SP=Speech pathologist
OT=Occupational therapist
PT=Physical therapist

Activity	Person	Location	APPROPRIATE FOR STUDENT? As is Y	As is N	With adapted materials Y	With adapted materials N	With adapted current goals Y	With adapted current goals N	With personal assistance	Specific adaptations
Recess	T,P	yard						•		adapt games
Open time	T	class			•					picture/word sched
Math	RC,T	RC			•		•			use manipulatives
Lang arts	T,A	class			•		•			use vocabulary from reading
Activity	T,P,A	class						•		T,Th
Science/ Social Studies	T,P,A	class					•	•		Use of A for hands-on activities, modified test
Recess/ Lunch	A,P	class						•		
Story time	T	class			•					sight words
Reading	RC,T	RC			•		•			flash cards, rebus
Art, Music Library	specials, T							•		A to assist
Gym	T	gym						•		adapt PE M,T,Th,F
Activity time	T,A,P	class						•		

Adapted from Thousand, J.S. (Project Director, September, 1986). The Homecoming Model: Educating students who present intensive educational challenges within regular education environments.

660

Positive Student Profile

This form is to be filled out by the parent to provide a "snapshot" of your child which should be reflected in his/her IEP.

1. Who is _____? (Describe your child, including information such as place in family, personality, likes and dislikes.)
2. What are _____'s strengths? (Highlight all areas in which your child does well, including educational and social environments.)
3. What are _____'s successes? (List all successes, no matter how small.)
4. What are _____'s greatest challenges? (List the areas in which your child has the greatest difficulties.)
5. What supports are needed for _____? (List supports that will help your child achieve his/her potential.)
6. What are our dreams for _____? (Describe your vision for your child's future, including both short-term and long-term goals.)
7. Other helpful information. (List any pertinent information, including health care needs, that has not been detailed elsewhere on the form.)

Adapted from: Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services, Beverly Rainforth, Ph.D., P.T., Jennifer York, Ph.D., P.T., Cathy Macdonald, M.A., C.C.C./S.L.P.

teacher who uses many hands-on and cooperative learning activities. Cooperative activities provided Angela opportunities to communicate with peers, group acceptance and a chance to participate in the same activities as the rest of the students.

• **Evaluation:** The quarterly meetings give Angela's team an opportunity to monitor her progress. Mrs. Brown provides the team with a narrative report card evaluating Angela's progress toward her IEP goals instead of a more traditional, grade-oriented student assessment.

• **Peer Supports:** At the beginning of the school year, Angela's teacher

RECOGNITION RESTORATION & REFORM

THE NATIONAL HEAD INJURY FOUNDATION

13th Annual National Symposium

November 6-9, 1994
Chicago Marriott Downtown, Chicago, Illinois

SYMPOSIUM HIGHLIGHTS

- A Gala Tribute Banquet for **Sarah & Jim Brady** hosted by **Helen Thomas**, *Senior White House Correspondent*
- Eleven full and half-day Pre-Symposium Courses
- Over 55 Sessions, including Plenary & Sub-Plenary Presentations
- Multiple Workshops, Symposia, Platforms & Poster Presentations
- Art for Creative Healing—A Visual Art Exhibition
- Opening Plenary Session featuring **Ben Vereen**, *Actor, Vocalist & Tony Award Recipient*
- Keynote Address presented by **Gerben DeJong, PhD**, *Director of National Rehabilitation Research Center*
- Annual Awards Luncheon hosted by **Mike Wallace**, *official spokesperson from NASCAR*
- The Sheldon Berrol, MD Lectureship by **George Prigatano, PhD**, *Chairman, Neuropsychology Clinical and Research Director, Neurological Rehabilitation Barrow Neurological Institute*
- The Second Annual Paul Spanbock Family Lecture, featuring **Muriel Lezak, PhD**, *Associate Professor, Oregon Health Science University*
- Exhibit Program featuring ten hours of exhibit time
- CEU credits & syllabus available

For more information write or call:
NHIF SYMPOSIUM SECRETARIAT
1150 S. Washington St., Suite 210, Alexandria, VA 22314. Phone: 703/684-6334. FAX: 703/684-6437

Circle # 251

123 123 123 123 123

A B C

Where kids can be kids!

Prescribed daycare facility
for medically complex children
Ages 3 months - 7 years

- Skilled Nursing Care
- Educational Development
- Therapy Services
- Infusion Therapy
- Interaction with other children in a developmentally stimulating environment

Tomorrow's Child
CENTERS FOR MEDICALLY DEPENDENT CHILDREN

Centers nationally located. For information call
(609) 354-9106

123 123 123 123 123

Circle # 215

talked with the class about her expectations regarding their attitudes and behavior toward Angela.

Initially, some children were hesitant to approach Angela. Mrs. Brown did not discipline them for feeling this way. A positive class environment allowed Angela to develop friendships.

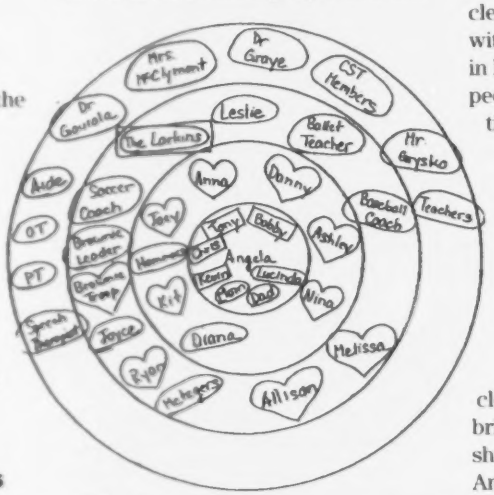
Specialized Assistance

Supports should be flexible; they should come and go as needed. If the team determines that specialized assistance is needed, look first within the school district for the added expertise. Avoid "quick fixes"—rather than flying an expert in for the day, seek an ongoing relationship with consultants. A consultant from the University-Affiliated Program of New Jersey worked with Angela's school district to help establish Angela's "circle of friends."

Angela's Circle of Friends

A "circle of friends" can help a student to become included. Angela's circle first met in June 1994. Thirty people came to the meeting—Angela's family, several child and adult friends, her Brownie leader, neighbors and the school principal and other educational professionals.

Individuals in Angela's innermost circle include her immediate family and closest friends—people who love her deeply and on whom she can depend the most. In the next circle are people who really like Angela and want to offer her support—many are Angela's peers. The third circle includes neighbors, coaches, Angela's Brownie troop and her troop leader—people Angela knows and likes to do things with. The outer circle are people who are paid to be with Angela—the many professionals in her life. Of course, many of these people also have strong emotional ties to her.



Many people with disabilities would have very few people to include in the second and third circles. Angela's inclusion in school and the community—as well as her outgoing personality—are reasons why her circle of support is so full.

The first meeting of Angela's circle began with her parents giving a brief history of her life. Members shared their dreams and fears for Angela. Then, each member of the circle shared his or her perception of

continued on page 84

Switch on the Fun

The Scanning 2-XL™ Talking Robot. Innovative, interactive, educational—and fun. Most importantly it is accessible using a single switch through scanning. Developed with the exceptional child in mind, it's the perfect playmate for learning and entertainment. The 2-XL tells stories and jokes, plays your child's favorite audio cassettes, asks questions and waits patiently for your child to scan and select the correct answer. A great gift for the holiday season. Order soon, as quantities are limited. Call or fax InvoTek today for a free catalog and pricing.

INVOTEK CORPORATION
700 W. 20th St.
Engineering Research Center
Fayetteville, AR 72701
(fax) 501-575-7446

2-XL™ is a registered trademark of Tiger Electronics.

1-800-576-6661
Providing Independence Through Technology

Circle # 211

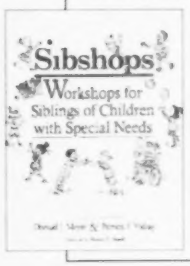
662

SIBSHOPS: Workshops for Siblings of Children with Special Needs

by Donald J. Meyer

Whenever I meet with parents, sibling relationships are one of the first topics that come up for discussion. Parents always tell me how helpful it would be for the sisters and brothers of children with disabilities to meet with other children from similar families.

I always agree. In the next breath, I tell them about Don Meyer, the creator of "Sibshops," and the wonderful work he has done in bringing these children together. I always urge parents to contact this dedicated and talented man to find out how they can do Sibshops in their own communities.



Finally, Don Meyer has put his vast experience into a fine book that will be useful to everyone who cares about the needs of the whole family. We are delighted to collaborate with the Paul H. Brookes Publishing Company to bring our readers a series of excerpts from this book.

SIBSHOPS is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910. –S.D.K.

For the adults who plan them and the agencies that sponsor them, Sibshops are best described as opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. They often reflect an agency's commitment to the well-being of the family member most likely to have the longest-lasting relationship with the person with special needs.

However, for the young people who attend them and the energetic people who run them, Sibshops are best described as *events*. Sibshops are lively, pedal-to-the-medal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, for others a not-so-good thing, and for many somewhere in between. They reflect a belief that brothers and sisters have much to offer one another—if they are given a chance. The Sibshop model intersperses information and discussion activities with new games (designed to be unique, offbeat, and appealing to a wide ability range), cooking activities, and special guests who may teach participants mime, how to juggle or, in the case of one guest artist who has cerebral palsy, how to paint by holding a toothbrush in your mouth. Sibshops are as fun and rewarding for the people who host them as they are for the participants…

Sibshops are not therapy, group or otherwise, although their effect may be therapeutic for some children. Sibshops acknowledge that most brothers and sisters of people with special needs, like their parents, are doing well, despite the challenges of an illness or disability. Consequently, while Sibshop facilitators always keep an eye open for participants who may need additional services, the Sibshop model takes a wellness approach…

Who Attends Sibshops?

Originally developed for 8- to 13- year-old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger and older children. It has been adapted for brothers and sisters of children with other special needs, including cancer, hearing impairments, epilepsy, emotional disturbances, and HIV-positive status. Sibshops have also been adapted for use with children who have experienced the death of a family member…

Who Sponsors Sibshops?

Any agency serving families of children with special needs can sponsor a Sibshop, provided it can offer financial support, properly staff the program, and attract sufficient numbers of participants. However, we strongly recommend that agencies work together to cosponsor a local Sibshop…

Who Runs Sibshops?

We believe Sibshops are best facilitated by a team of service providers (such as social workers, special education teachers and professors, psychologists, and nurses) and adult siblings of people with special needs. At the very least, the team of facilitators will need to: be knowledgeable of the disability or illness represented, possess a sense of humor and play, enjoy the company of children, and respect the young participants' expertise on the topic of life with a brother or sister with special needs…

663

Helping Children Shape Their Lives

Our caring staff is committed to helping children shape their lives through personal choice and a solid foundation of learning.

Specialized education and therapy programs are tailored to meet your child's needs.

Working together, we can help them reach their goals.

. . . Right From The Start

Elwyn Inc. day and residential programs, include:

- early intervention
- pre-school for disabled and non-disabled children together
- elementary and secondary education
- post-graduation transitional services
- vocational training and placement
- award-winning therapeutic recreation facilities
- 24-hour health care services
- modern, home-like residential settings

Elwyn, caring for over 10,000 children and adults with varying disabilities, has locations throughout Pennsylvania, New Jersey, Delaware, California, and Jerusalem.

ELWYN INC. • Admissions Office
111 Elwyn Road • Elwyn, PA 19063-4699
(610) 891-2256 (PA) • (800) 345-8111 (outside PA)

Circle # 172

What Is The Optimal Number of Participants For A Sibshop?

Sibshops have been held for as few as 5 children and as many as 45. Around a dozen children, with at least two facilitators, is a comfortable number…

When Are Sibshops Offered?

Usually Sibshops are offered on Saturdays, often from 10 a.m. until 2 p.m. This allows ample time for games, discussion and information activities, and making and eating lunch. Of course, Saturdays from 10:00 to 2:00 will not be ideal for all families or communities…

How Often Are Sibshops Held?

Depending on the needs and resources of the community, Sibshops may be offered as frequently as weekly (as with a one-and-a-half-hour after-school program) or as infrequently as yearly (as with an all-day Sibshop that is a part of an annual conference for families from around the state or nation). Generally, Sibshops are presented monthly or bimonthly…

What are the goals of the Sibshop model?

Goal 1: *Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.*

The chance to meet other brothers and sisters in a casual atmosphere and join them in recreational activities has several benefits for participants. First, it can help reduce a sibling's sense of isolation…

Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Friendships begun during Sibshops and continued outside the program offer siblings ongoing sources of support.

Third, the recreational aspect of the Sibshops makes them enjoyable to attend. If children perceive the Sibshop as yet another thing that they have to do because of their sibling, they may find it hard to be receptive to the information and discussion presented in the workshop…

Goal 2: *Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.*

At Sibshops, participants share stories, experiences, and knowing laughs with peers who truly understand the ups and downs of life with a sibling who has special needs. This opportunity allows participants to learn that they are not alone with their experiences and their often-ambivalent feelings.

Goal 3: *Sibshops will provide brothers and sisters with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.*

Brothers and sisters of children with special health

and developmental needs routinely face situations that are not experienced by other children. Defending a brother or sister from name-calling, responding to questions from friends or strangers, and resenting the time and attention required by the sibling with special needs are only a few of the problems siblings may experience. At a Sibshop, participants learn how others handle difficult situations. This experience can offer a sibling a broad array of solutions from which to choose...

Goal 4: *Sibshops will provide siblings with an opportunity to learn more about the implications of their brothers' and sisters' special needs.*

...Brothers and sisters have a need for information to answer their own questions about their siblings' special needs as well as the questions posed by friends, classmates, and strangers...

Goal 5: *Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.*

Because they may be unaware of the wide range of sibling concerns, some Sibshop activities attempt to help parents and service providers better understand "life as a sib." One activity allows parents and professionals to meet with a panel of young adult and adult siblings to learn about the special joys and challenges of growing up with a special brother or sister. Parents learn about what the panelists appreciated in their parents' treatment of the children in their family, and also what they wish their parents had done differently...

Donald J. Meyer is the director of the Sibling Support Project at Children's Hospital and Medical Center in Seattle. Funded by the U.S. Department of Education, Special Projects, the Sibling Support Project seeks to increase the number of peer support and education opportunities for brothers and sisters of children with special needs through training, demonstration and technical assistance.

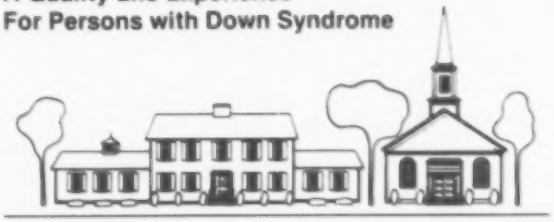
Don was a founder of the Supporting Extended Family Members program which pioneered services for fathers, siblings and grandparents of children with special needs. During the past 14 years, he has written curricula, chapters, articles and a book for children. He has also made many presentations to parent and professional audiences throughout the U.S. and Canada.

SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS details the program that won the 1992 National Award for Innovation from the Association for the Care of Children's Health.

Don is the younger brother of two siblings who have epilepsy. He is married and the father of four children.

Pathfinder Village

A Quality Life Experience
For Persons with Down Syndrome



In this picturesque colonial village, located in scenic central New York State, life is full of wholesome activities and rewarding opportunities. Residents with Down Syndrome experience the joy and personal satisfaction of learning, working, and participating in a vital, dynamic community. Our year-round, co-ed program includes education, recreation, and employment opportunities plus the chance to live life to the fullest. *Call us today.*

R.R. #1, Box 32-A, Edmeston, NY 13335
Telephone (607) 965-8377

Circle # 161

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

Halloween Magic

Making a wheelchair part of a Halloween costume

by Juanita Stotts

Do you feel like your child is lost in his Halloween costume when you put him in his wheelchair? Why not make the wheelchair a part of the costume?

Costume ideas for your child and his wheelchair are endless. Let your child decide what he would like to be for Halloween, then expand on that idea for the chair. For example, a policeman can sit in a policeman car, a fireman can drive a fire engine or a flower can grow out of a pot.

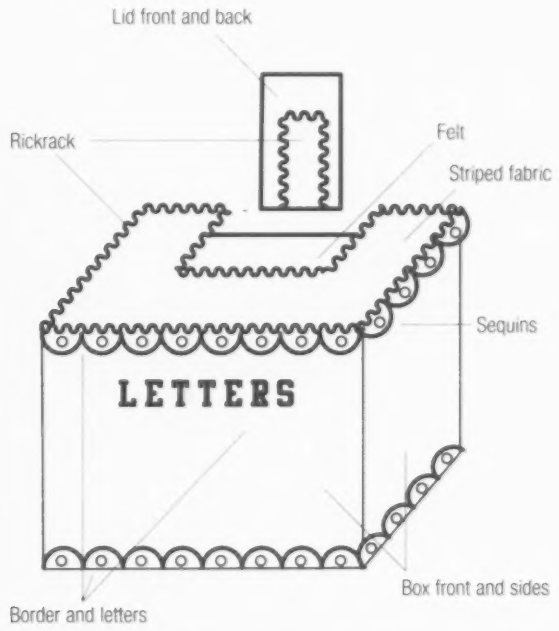
These directions are for a jack-in-the-box wheelchair costume, but the same basic steps can be used to create many different costumes. It's a fun project you can work on with your child in whatever way he can participate.

Jack-in-the-Box Supplies:

One large box: The size of the box depends on the wheelchair. The box must be big enough to slide onto the wheelchair easily, and must fit over armrests and the tray. It must clear the ground by at least two inches.
Fabric: You will need enough striped fabric to cover three sides of the box and part of the top. You will need enough solid-colored felt to cover the top of the box and create decorative borders and lettering.
Decorations: Sequins, rickrack.
Other: glue, adhesive-backed Velcro.

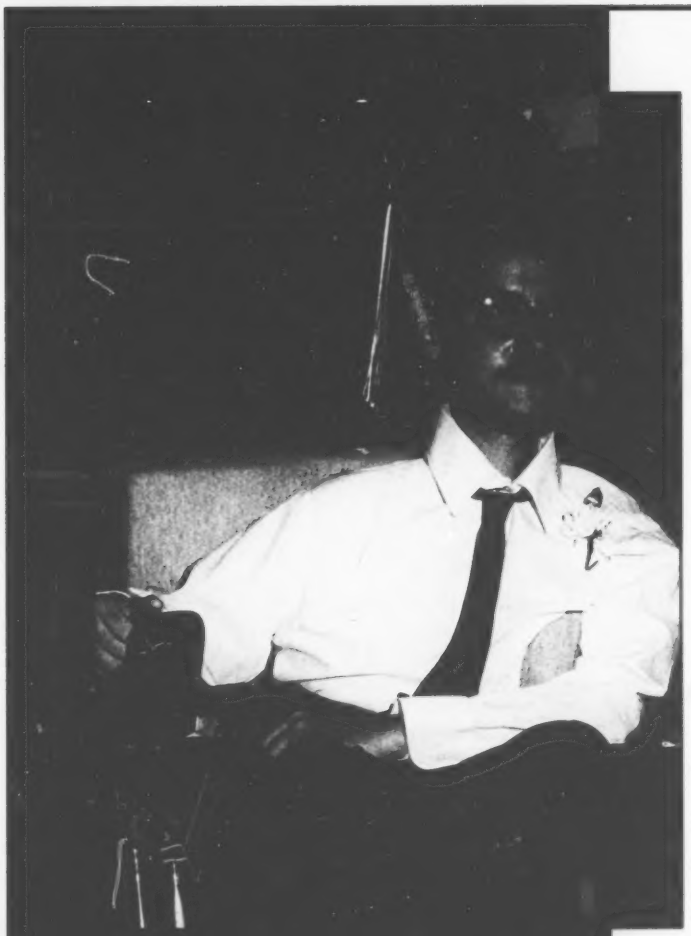
Directions:

1. Cut the box: Begin by cutting the flaps off one end of the box. This will be the bottom. Next, cut off one side of the box for the back opening. Cut this piece in half and set it aside to use as the jack-in-the-box lid. With the flap side up, place the box over the wheelchair tray or armrests. Fold down the three flaps for the top and glue together securely. Make any necessary cutouts for wheels, brakes or table top.



2. Cut the striped fabric so it covers the three sides of the box and overlaps six inches on top. First, glue the fabric to the sides of the box. Next, fold down the top two sides and glue. Finally, fold the front flap down and glue.
3. Cut a square piece of felt slightly larger than the area remaining to be covered on the top of the box. Glue into place.
4. Take the piece of cardboard that you have set aside to use as the jack-in-the-box lid. Cover it on both sides with striped fabric and glue.
5. Cut a scalloped border from felt for the top and bottom edges of the box. Glue into place.
6. Use stencils to trace letters on felt. Cut the letters out, position them on the box and glue into place.
7. Add finishing touches: Glue rickrack around the lid, the square of felt on the box top and the top edge of the box. Glue sequins onto the felt borders. Attach the lid to the back of the chair using Velcro.

666



Crotched Mountain Rehabilitation Center serves a multiply-handicapped population with the finest combination of contemporary technology, sophisticated learning theory, a beautifully engineered environment, compassion, and caring. Any resident being served in this program is fortunate and is receiving the very highest standard of care, treatment and education.

New York State
Multiagency Review Team, 1993

Exceptional Needs . . . Exceptional Outcomes

Crotched Mountain Foundation is proud to announce its capacity to facilitate community-based housing and aftercare for students returning from residential settings to cities and towns in New York, Maine, and New Hampshire.

Crotched Mountain can provide your child with state-of-the-art educational and rehabilitation services in a preparatory school setting, followed by a guided return to your community housing, educational, and lifelong planning resources.

For more information on these services or those of our subsidiaries, please contact our Admissions Officer, Debra Flanders at (603) 547-3311, ext. 235.

CROTCHED MOUNTAIN

A subsidiary of the Crotched Mountain Foundation
1 Verney Drive, Greenfield, NH 03047, (603) 547-3311

Circle # 17

"Hand over hand into the future!"

A community of alternatives for children, adolescents and adults who may be physically, mentally, or medically challenged.

M Approved Private School (Extended School Year)

E Summer Activity Program

Adult Vocational and Day Programs

L Physical and Speech Therapies

Occupational Therapy

M Aquatic Therapy

Therapeutic Horsemanship

A 24-Hour Nursing

Personal Care Homes

R Residential Cottages

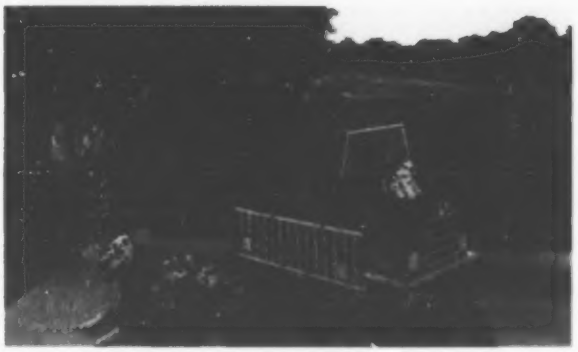
Respite Care

K Center For Independent Living

Home of *"The Country Garden Guild"* and *"The Joybells"*

Wayland Road, Berwyn, PA 19312
Phone (610) 353-1726
Fax (610) 353-8528

Circle # 253



The same basic steps that go into the jack-in-the-box costume can be used to create many different costumes. In this photo, Benjamin Stotts and his wheelchair become a fireman and his truck. The family's Dalmatian, Razzy, adds a touch of authenticity.

Dress your child up in a clown costume which coordinates with the striped colors of the fabric on the box. He will be very proud of his costume, and he surely will get noticed. My son, Benjamin, did!

Juanita Stotts lives in Mesa, Arizona with her husband, Joe, and children, Benjamin, 5, and Rachel, 4. Juanita studies writing, and Joe is a general contractor. Benjamin has static encephalopathy and attends a special education class at Franklin Elementary School in Mesa.

Earn-A-Bike

Yes You Can!

Many models to choose from!

Call Now
1-800-654-9664
Office hours: 8:30 am - 5:00 pm Mon.-Fri. Central Standard Time

CALL NOW FOR A FREE VIDEO INFORMATION KIT. DON'T FORGET TO ASK ABOUT THE NEW EARN-A-BIKE PROGRAM.

You can get your therapeutic cycle for FREE!

Rock N' Roll Cycles
P.O. Box 1558 • Levelland, Texas 79336

Circle # 232

Dear Timmy...

by Wayne Stauffer

I have learned so much from you that I should be learning from your brothers who do not have disabilities.

Forgiveness. Patience. Love. Kindness.

And I am not finished with my education; I learn something new from you every day.

I learn I am not the center of the universe. The evening news will still be as depressing even if I don't see it because I'm helping you eat, do your homework or organize one of your collections. Books will wait to be read; my students' papers will wait to be graded. This article will take longer to write because I took a few seconds to turn on a light you can't reach. I can be selfish about my time and about the things I want to do, but I will always have "Dad time" for you.

I improve my problem-solving skills by figuring out how to get you into the rides at AstroWorld, the bleachers at the Dome or the seats at the movie theater. I no longer take aisle-width for granted as I did before you came into my life. I now can judge wheelchair-width pretty well. And I'm working on the job possibilities that will be available to you in less than 10 years.

I take more time to examine the important things—like toads, blossoms and rabbits in the tall grass—because I'm looking for things to point out to you.

I learn not to take myself so seriously. Your slapstick sense of humor helps me see that it *is* funny when I dance in pain after dropping a box on my foot or shake my hand after hitting it with a hammer.

I learn that the little things in life are important—a give-away pen from a convention, a toy from a fast-food kid's meal, a two-minute call home, a trip to the corner to gas up the car or to the hardware store to get the right plumbing joint.

I learn that it's not the amount of time I spend with my children that counts—it's the timing. Being there at the right time—Timmy, you remind me of this every day. The day you went into surgery to have nine silver caps put on your teeth, I got stuck in the rain. By the time I finally got there, you were out of the operating room and slowly recovering from the anesthesia. You were fine, but I missed being there for you before you went in.

I was working the day you walked for the first time. The surgery a few days earlier had gone as planned, and you were able to walk with a walker sooner than expected. If the therapists had not videotaped it, I would have been unable to share in your triumph.

But I was there to help soothe your dignity the day you fell face-first in the playground's sand pit. You were doing so well walking in the sand with your walker. Then, the front got stuck and you went down before I could catch you. All I could do was help you get up, clean off the sand and be there to share your embarrassment.

You remind me every day that although your cerebral palsy *affects* who you are, it does not *define* who you are. There is much more to Timmy Stauffer than the cerebral palsy that keeps him from standing without a walker and causes him to lose his balance in a chair without armrests.

Wayne Stauffer is a technical writer, junior high English teacher and community college instructor who lives in Houston, Texas with his wife Debbie, twin sons, Andrew and Timmy, and their younger brother, Mark. He is looking for a publisher for several short stories he has written for chil-

669

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

☐ I'm interested in community involvement. Please send more information about Civitan service clubs in my community.

☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name _____

Address _____

City/State/Zip _____

Telephone Number ( ) _____

CIVITAN INTERNATIONAL, P.O. BOX 130220, BIRMINGHAM, AL 35213 **(800) CIVITAN**

Circle # 186

Providing Quality Services for Children and Adults with Autism and Related Developmental Disabilities

LEAGUE SCHOOL OF BOSTON

Day	Residential	Farmstead
Early Intervention - Age 22	Ages 6-22	Age 18 - Adulthood

Twelve Month Day Educational Programming

Specialized Community Residences

Early Intervention and Home Training

Community Based Supportive Employment and Vocational Training

After School Recreational Programs

Friendship Farms - Adult Farm Living in the Heart of Cranberry Country

League School of Boston, Inc.
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260

Herman T. Fishbein
Executive Director

Accreditation: Massachusetts Dept. of Education, Office for Children, Dept. of Social Services, Dept. of Mental Retardation, Dept. of Mental Health, NY Dept. of Education

Circle # 200

Your cerebral palsy does not have to limit you from realizing your dreams. Your problem is not really cerebral palsy. It is getting others—people with small imaginations—to expand their ideas about the special qualities and unique abilities that make all people successful.

These are things I should be learning from your brothers, who don't have cerebral palsy. But if it weren't for you, I don't think I'd be paying attention to these lessons. Because your brothers can fend for themselves on most occasions, I tend to take them for granted more than I should.

Since I can't take you for granted, I make sure to listen to you more closely, and this reminds me to listen to your brothers, too. You help me to be a better dad. Thanks.

All my love,
Dad

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

670

Cut From the Same Bolt of Cloth

Abby's escapades help Sheila's mother gain a new perspective

by Nancy Holroyd

"Abby, AB-by, AB-BY!"

I chuckle, not to offend the woman calling to her child, but out of a sense of relief. That mother's voice has that exasperated tone I often hear in my own voice when Sheila is running off on her own little tangent. There have been times when I wondered if Sheila ignores me and does what she wants because she has Down syndrome. But Abby is a "normal" child.

By the end of choir rehearsal, it is clear to me that Abby and Sheila were cut from the same bolt of cloth—even if Sheila's section of the bolt had an altered thread count. Since that day, about three years ago, I have continued to watch Abby and Sheila develop and grow. To be sure, I see differences, but the similarities are striking.

Sheila Holroyd (left) enjoys a hug from big sister Andrea.

Eating Flour

One day, early in the Christmas season, I set out to bake cookies. Sheila, who loves to "help," joined me in the kitchen. Declaring loudly, "I do dat," she helped me add ingredients and stir them together.

I turned my back on her long enough to turn on the oven. When I turned around again, flour was flying. Sheila was merrily stuffing her fists—both full of flour—into her mouth. As I cleaned up the mess, I attributed Sheila's behavior to her Down syndrome. What normal child would eat flour?

That night, my husband and I headed out to a party with the cookies Sheila had helped me make. It was a festive affair, with a tree waiting to be decorated by guests and the host's children. The attendees were a congenial group of folks—fellow church members, Abby's parents among them.

Abby's mother is a great storyteller, and I soon heard peals of laughter as Jean regaled the group with Abby's latest escapade. I listened to her story and stood there thunderstruck—"You mean *Abby* eats flour, too? Sheila did the same thing this afternoon. I thought it was because she has Down syndrome!"

Just Trying to Help

Sheila goes at her own pace, but her development follows typical patterns. In some areas, her delays are very apparent. In others, they are not so easily noticed. Sheila has a long way to go, but she is well on her way—just like the rest of our children.

In one area, Sheila is way ahead of her older sister; she is quick to notice what needs doing and tries to jump right in and "help." Sometimes her help is of the "who-needs-it" variety. Like the day she opened the refrigerator door because she thought the baby was hungry. The eighteen-month-old grabbed an open can of peaches and spilled it. Sheila tried to wipe up the sticky peach juice with a small wash cloth. I was in the basement wrestling with the laundry during this caper.

I didn't laugh until much later, but even while scrubbing the floor in front of the refrigerator, I knew Sheila was only trying to be helpful. For all the mischief she can get into, there is a thoughtful quality about her that far outweighs some of her lagging skills.

More Alike Than Different

Our friendship with Abby's family has been invaluable. It helps me keep some things in perspective. It is too easy to attribute all of Sheila's misbehavior to her disability. It is easy to lose sight of normality when society keeps reminding me that our family is different.

Abby's antics have taught me that Sheila's age and personality have a lot to do with her behavior—perhaps more than the Down syndrome does. And at those times when she is exasperating me the most, I know there is probably another little girl—"normal" in her development—having the same effect on her mother.

Nancy Holroyd lives in Duanesburg, New York with her husband, Forrest, and daughters, Andrea, 9, Sheila, 7, and Colleen, 3. Sheila attends a local school where she is fully included. Nancy is the editor of NEWS & NOTES, *the newsletter of* DOWN SYNDROME/AIM HIGH!, *a local Down syndrome support and advocacy group. For the last two years, Nancy has served on the Educational Directions Committee in her local school district.*

One size does not fit all!

Children's Specialized Hospital is dedicated exclusively to serving the special needs of children and adolescents.

- Child Study Team
- Learning Disabilities
- Attention Deficit Disorder
- Early Intervention / Pre-School
- Speech and Hearing
- Occupational Therapy
- Physical Therapy
- Cognitive Remediation
- Day Hospital

Children's Specialized Hospital

MOUNTAINSIDE • FANWOOD • TOMS RIVER
For Information Call (908) 233-3720

Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation" — the highest distinction awarded by the Joint Commission on Accreditation of Healthcare Organizations.

Circle # 185

THE DIRECTORY FOR EXCEPTIONAL CHILDREN

Totally revised and updated, *The Directory for Exceptional Children* includes over 3000 schools, facilities and organizations across the United States. Listings encompass the entire range of developmental, organic and emotional handicaps.

Both public and private facilities are covered—boarding schools, outpatient clinics, and residential and day facilities—and the availability of summer sessions is noted.

Write for brochure and order form.

PORTER SARGENT PUBLISHERS, INC.
11 Beacon Street, Suite 1400
Boston, Massachusetts 02108
Tel. 617-523-1670 • FAX: 617-523-1021

Circle # 249

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution

- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

Order Now by Calling 1-800-647-8887

Available in Black or Beige

TEMASEK TELEPHONE INC.
21 Airport Blvd. #G, So. San Francisco, CA 94080

Circle # 202

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: CRI
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle # 162

672

Dental Care for Children with Disabilities PART TWO

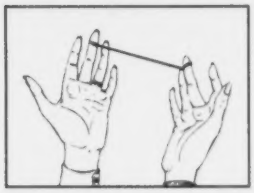
Brushing, Flossing and Rinsing

by Steven P. Perlman

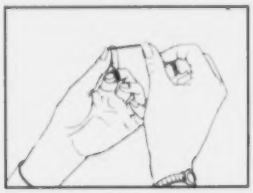
FLOSSING

Brushing is not enough. Flossing is needed to remove plaque between the teeth, where a toothbrush can't reach.

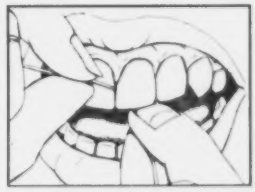
Step-by-Step Flossing



Take an 18-inch piece of floss and wind it around the middle finger of each hand. Or tie ends together in a circle.



Grasp the floss firmly between the thumb and index finger of each hand. Hold a half-inch section taut for more control. Work it gently between teeth until it reaches gumline.



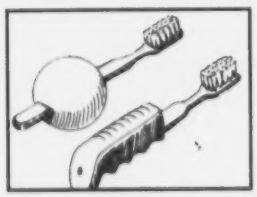
Curve floss into a C-shape around tooth. Slide floss up and down side of tooth gently. Remove floss gently and repeat for all teeth. Be careful not to injure gums with floss.

BRUSHING

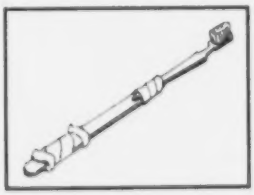
If the child gags easily or cannot spit, brush his teeth with a fluoride rinse instead of toothpaste. First, brush without the rinse. Then, pour a little rinse into a cup, dip the toothbrush into it, and brush with the rinse.

Adapt a Toothbrush

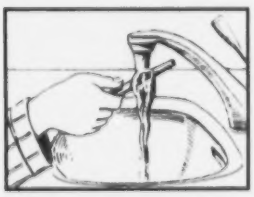
Attach the brush to the child's hand with a wide elastic band.



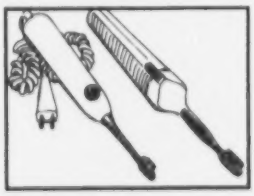
For children with limited grasp, enlarge the brush handle with a sponge, rubber ball or bicycle-handle grip.



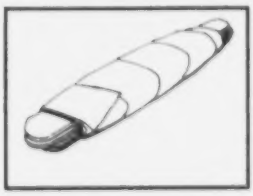
For children who cannot raise their hand or arm, lengthen the brush handle with a ruler, tongue depressor or long wooden spoon.



Bending the brush handle may make it easier for some children to grasp. The handle will become soft enough to bend after running hot water over it. Do not run hot water over the head of the brush.



For a child who cannot manipulate a regular toothbrush, an electric toothbrush may allow him to brush his teeth independently.

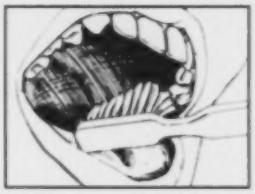


If the child cannot keep his mouth open, use a mouth prop—for example, three or four tongue depressors taped together, a rolled-up moistened washcloth or a rubber doorstop. Ask your dentist how to use a mouth prop correctly so you can avoid injuring the child's mouth.

673

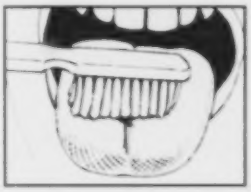
Step-by-Step Brushing

Start with the upper teeth, brushing outside, inside and chewing surfaces. Repeat for the lower teeth. Be sure to brush each tooth.



Place the toothbrush bristles at the child's gum line, at a 45-degree angle to the gums. Press gently and use short strokes with a vibrating, back-and-forth or light scrubbing motion.

Reposition the brush vertically to clean inside the surfaces of front teeth, both upper and lower.



To freshen breath, brush tongue, too. The tongue can harbor many odor-causing bacteria.

GROWTH AND DEVELOPMENT CHECKLIST

1. Try to minimize thumb-sucking, finger-sucking or pacifier use. These habits may cause future malocclusions (bite abnormalities).
2. Keep an infant's gums clean to reduce teething discomfort. Clean the gums with a piece of gauze or a washcloth.
3. The American Academy of Pediatric Dentistry recommends that a child have his first dental exam within six months of the first tooth's eruption and no later than 12 months of age. At this time, a dentist can check for proper tooth growth and development and the possibility of dental decay.

Good early experiences with the dentist will help the child develop a positive attitude toward the dentist, so he will be more likely to cooperate during future dental visits.

St. Coletta School, founded in 1904 in a pastoral farm setting, offers a year-round residential program. Each person is a unique individual with God-given potential to live a personally satisfying and productive life. The varied aspects to daily living -- education, home life, recreation and leisure activities, vocational training, employment opportunities and community transitional group homes are options available to make the most of an individual's interests and abilities.

A tuition-based facility, St. Coletta's presently serves almost 600 persons ages 7 through 94 who have mental retardation, many of whom have multiple handicaps. Special services include personal and vocational counseling, socialization skills training, personal living and transitional home living skills, language and speech therapy, music, art, therapeutic recreation, adaptive physical education, swimming and physical/occupational therapy.

In A World
Where Love
Is Sometimes In
Short Supply

We Have It In Abundance

NINETY YEARS

St. Coletta School
Jefferson, Wisconsin 53549

Sponsored by
The Sisters of St. Francis of Assisi

Our Alverno ICF/MR program continues to provide quality care for adult residents, carefully balancing spiritual, social and emotional growth in a pleasant and attractive setting. Qualified staff and stimulating activities are of special interest to families seeking comprehensive care. The Alverno program is a certified T-19 provider with an active treatment program.

For further information, contact the Admissions Office at (414) 674-4330, Ext. 226.

Circle # 74

4. Avoid "nursing-related caries." Do not put a child to bed—even for a nap—with a bottle of sweetened liquid (such as milk, formula or fruit juices) in his mouth. When the child is sleeping, a decrease in salivary flow allows the sugary liquid to remain in the child's mouth for an extended period of time. This causes tooth decay. Breast-feeding over a long period of time can cause a similar problem.

If the child needs a bottle at bedtime, fill it with water or a noncarbonated, artificially-sweetened liquid like a fruit-flavored drink or iced tea.

Good early experiences with a dentist will positively influence the child's behavior and attitude during future dental visits.

5. Note that some liquid medications contain from 30 to 50 percent sucrose. This includes medications used for heart disease, seizures or recurrent infections. When these sugar-laden oral medications are given to a child before naps or at bedtime—when salivary oral flow is diminished and will not wash the liquids out of his mouth—tooth decay may result.

Medications should be given during the child's waking hours. After a dose, have the child rinse thoroughly. If possible, have him brush, too. Inform your dentist about the medications the child is taking, and the frequency and time of day medications are given.

6. The eruption of primary and permanent teeth takes place at different ages in different children. Frequent dental care—visiting the dentist at least once every six months—can help to insure proper guidance of developing teeth and, if necessary, early intervention for developing bite abnormalities.

7. If the child's permanent tooth is erupting before the primary (first) tooth has fallen out, seek care as soon as possible. Prompt removal of the primary tooth can prevent the development of orthodontic problems that may be difficult to correct in the future.

8. If tooth crowding is present, an early orthodontic consultation is advisable. Certain procedures may be done to limit or possibly avoid extensive orthodontic treatment later.

This article has been adapted with permission from materials originally published by Johnson & Johnson Dental Care Company.

FREE ASSESSMENT shows how much you can save

Increase Cash Flow, Cut Time & Costs For Handling Medical Claims

Get Your Insurance Claims PAID in 13 Days

Claims an expensive headache? Just call Medical Claims Processing Systems for a FREE no-obligation assessment of your billing system.

Within a month, MCPS can reduce the time you and your staff spend on billing by 65% or more. This means more time for patient care, more time for appointments!

MCPS lowers billing costs, too! Discover how we custom-tailor an affordable electronic insurance claims system for your practice that:

- **Is Fast, Accurate and Complete**
- **Eliminates Tracing**
- **Handles Medicare, Medicaid, Medical PIP, and Workers Comp.**
- **Achieves Timely Claims Payment**
- **Increases Cash Flow**

"MCPS saves me time every month. Looking back, I don't know how I managed without it." -- *K. Cirino, Office Manager, Physicians Office*

"They sped up claim payments and eliminated tracing."-- *R. D. Santucci, D.C.*

"Our time is better spent caring for patients. No more chasing paper or computer hassles."-- *Theodore P. Sgambati, Jr., MD*

CALL TODAY - 201-489-5190

Ask for Ron Richards, President

Medical Claim Processing Systems

675

Circle # 252

A MOST ACCESSIBLE STORE

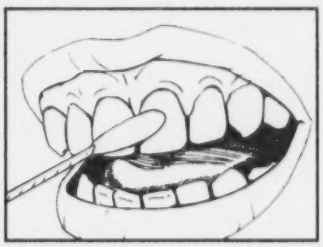
The Apple Computer Disability Solutions Store
Call: 1-800-600-7808; 1-800-755-0601(TTY).

RINSING

Daily rinsing with a fluoride rinse can provide additional protection against cavities by strengthening tooth enamel.

Step-by-Step Rinsing

The child takes the recommended dose of a fluoride rinse (usually a capful), swishes it around his mouth for 60 seconds, and spits it out. The child should be careful not to swallow it. To get full fluoride protection, the child should not eat or drink for 30 minutes after rinsing.



If the child is unable to rinse without swallowing, use a cotton swab or toothbrush to place a little fluoride rinse on his teeth. Your dentist may also recommend a prescription, fluoride-gel treatment.

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to maintaining a private practice in Lynn, Massachusetts, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their "Special Athletes, Special Smiles" program. Dr. Perlman lives in Swampscott, Massachusetts with his family.

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America.
Steel frame. Duel caliper, drum and coaster brakes available.
Parking brakes standard.
Latest styling and wide choice of colour combinations.
More than 30 specially designed accessories to meet every need.

ORTHOPAEDIC CYCLES

Circle # 36

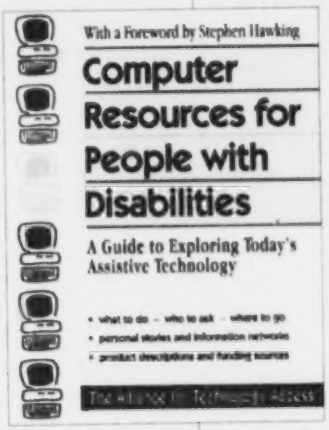
676

MEDIA

This wonderful new book is another example of the power of parents to change the world. Less than 10 years ago, a few parents recognized that technology could help their children with disabilities. They began a collaborative effort which became the Alliance for Technology Access, a nationwide network of community-based assistive technology centers. Today, these centers serve thousands of children and adults with disabilities, parents and professionals. Now, this group has produced their first book—an overview of hardware, software and other adaptations which give people with disabilities equal access to computer technology.

We will be collaborating with this outstanding group to create editorial material for the November issue —our 12th annual technology issue.

—S.D.K.


With a Foreword by Stephen Hawking
Computer Resources for People with Disabilities
A Guide to Exploring Today's Assistive Technology

Imagine having a keyboard that changes effortlessly from a standard layout to one that includes only the keys you need for a specific task… Imagine a computer that talks to you, that reads messages sent to you from all over the world. Imagine having the ability to make choices by simply touching a picture on your computer screen. Imagine having the ability to type without using your hands by simply looking at the right letter on a keyboard pictured on the screen. Imagine going to the Library of Congress to gather materials for a research project without ever leaving your home.

These scenarios are just a few examples of what you can do today with computers. For a person with a disability, today's applications offer new promise and excitement. These new abilities level the playing field for all of us.

Why This Book Was Written

…We want to share with you what we have learned about the ways assistive technology is literally changing lives by creating new abilities for children and adults with disabilities—sensory, cognitive, learning or physical disabilities.

Everyday, in the course of our work, we are asked questions about available technology and its applications. "I have a vision impairment. Which computer should I buy?" "My son has a learning disability and his teacher said a computer might help him do better in school. Which should I buy?" "I have a girl in my sixth-grade class with cerebral palsy, and the school has agreed to provide her with a computer. Which is the best?" Your questions may be similar.

The goal of this book is to help you begin answering your questions for yourself, and to allow you to take advantage of the incredible new tools on the market today. We won't teach you about the insides of the latest computers or list every computer product ever developed. Our intention is to help you create a purpose and a framework for approaching technology so you can make initial decisions about the role it can play in enhancing your life. We have included many stories about real people who are using technology successfully—people of all ages and all disabilities…

This book is written for a community that has not yet discovered the power of technology. This community includes people with disabilities, but it also includes family members, advocates and friends of people with disabilities. It encompasses thousands of professionals in the fields of education and rehabilitation who are concerned about quality-of-life issues and options for children and adults with disabilities. It includes the technologists, engineers, and designers who will be the developers of tomorrow's technology. This broad group represents a huge constituency that will be dramatically impacted by technology in this and the next century…

Structure of the Book

The book is divided into three parts. *Part I, The Search for Solutions,* will guide you through the process of defining your needs, developing a technology plan, building a supportive team and making technology-related decisions…

Part II, The Technology Toolbox, focuses on the technology itself… helping you to zero in on the technologies most likely to match your abilities and goals… You will learn enough about the categories of products on the market today to feel comfortable taking the next steps…

Part III, Helpful Resources and References, contains lists of resources, references and organizations that we have found valuable…

Much of what we offer are the right questions and some key resources. If you find that, after reading this book, you have a goal in mind, some easy first steps to take and a range of supporters to help; if you are armed with enough information to talk comfortably with your local computer dealer; or if you are inspired or excited by someone's story, we have accomplished our goal.

Excerpted from COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES, *written by the Alliance for Technology Access, published by Hunter House Publishers, Alameda, California. This book is available through* EXCEPTIONAL PARENT LIBRARY, *(800) 535-1910.*

677

Crystal Springs School

A PROGRAM OF THE
INSTITUTE FOR DEVELOPMENTAL DISABILTIES, INC.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availability.
- Licensed by the Massachusetts Office for Children.
- Approved by the Massachusetts Department of Education.
- Member of the Massachusetts Association of Approved Private Schools.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537
Circle #151

Circle # 151

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages, inc.
A Model, Supportive Community
For Mentally Retarded Adults
664EP School Street, Pembroke, MA 02359 (617) 293-5461

Circle # 55

Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 750-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Circle # 77

Exceptional Programs For Exceptional Children.

At St. Coletta Schools we believe life is what happens today. Our goal is to provide the best possible life experience for your exceptional child. Students here are not only preparing for tomorrow, they are living quality lives everyday. Founded in 1947, St. Coletta Schools offer a wide range of programs for children with mild to severe developmental disabilities. Twelve-month residential and day programs for ages 6-22.

- Extensive Vocational Training
- Functional Academics
- Community Skills Training
- Daily Living & Social Skills
- Adapted Phys. Ed. & Recreation Activity Program
- Special Olympics
- Behavior Management
- Physical & Occupational Therapy
- Speech Therapy
- Music, Art & Computers
- Prader-Willi Program

St. Coletta's
OF MASSACHUSETTS
John W. Shyne, Jr., President

Cardinal Cushing School & Training Center
400 Washington Street, Hanover, MA 02339
Braintree St. Coletta Day School
85 Washington Street, Braintree, MA 02184
Contact: Lynne Goyuk
Tel: (617) 826-6371
Fax:(617) 826-6474
Sponsored by
The Sisters of St. Francis of Assisi of Milwaukee, WI

Circle # 73

Annandale Village

Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY ... WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.
- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710

BREHM PREPARATORY SCHOOL

Blue Ribbon School 1992-1993

1993 BLUE RIBBON WINNER
Brehm Preparatory School is a Midwest boarding school designed to meet the academic, social, and emotional requirements of adolescents, age 12-21, with learning disabilities. Brehm offers specialized academic instruction, Orton training, speech and language therapy, and social skills guidance. Certified staff, family atmosphere, NCA accredited.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
[618] 457-0371

Camp Huntington

33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

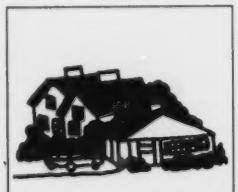
A point of light

CHILEDA HABILITATION INSTITUTE Educators for youths with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Estab. 1973.
- Intensive
- Progressive
- Specialized

Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608)782-6480 / (608)782-6481 (Fax)

THE DUVALL HOME, EST. 1945. A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:
- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874
(800) 358-0450



"MAXIMIZING INDIVIDUAL POTENTIAL"
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

OAK HILL SCHOOL
100 Years of Compassion
Exceptional people deserve exceptional care. CIB/Oak Hill School enters its second century of compassionate care and ground-breaking education for children and adults with severe developmental disabilities.
- Residential living
- Day and vocational programs
- Loving, supportive environment
- Dedicated, highly-qualified staff

CIB/Oak Hill
120 Holcomb St.
Hartford, CT 06112
(203) 242-2274

RESPITE SERVICES provides short term residential care for children, adolescents and adults with disabilities. Respite Services gives a weekend break, vacation or help in times of illness or other crisis. Summer camp sessions are also available. Family style care and welcome in a country setting.

Contact: John & Pat Ryan
Respite Services
RRI Box 458
S. Gibson, PA 18842
(717) 756-2750
(717) 756-2870 Fax

Special Force Family Ministries

A PLACE TO CALL HOME
Special Force Family Ministries operates superior quality residential programs for adults with mental retardation in private homes near Minneapolis, MN and Springfield, MO. Residents become members of individual families where Christian values are affirmed. Community involvement. Recreational opportunities. Affordable rates. Established 1973. Call for details.

Contact:
Special Force Family Ministries
P.O. Box 47, Waconia, MN 55387
(612) 442-4441

SCHOOLS, COLLEGES, & RESIDENCES

NATIONAL HOTLINE SERVICE

National Christian Resource Center on Mental Retardation Bethesda Lutheran Home & Service
700 Hoffman Drive
Watertown, WI 53094
(800) 369-INFO
See ad on page 74

CONNECTICUT

Intensive Education Center, Inc.
27 Park Road
West Hartford, CT 06119
(203) 236-2049

FLORIDA

Ralph J. Baudhuin Oral School
3301 College Avenue
Ft. Lauderdale, FL 33314
(305) 475-7324
A humanistic learning environment for children, birth–8th grade with communication disorders, learning disabilities and ADD.

Threshold, Inc.
P.O. Box 1110
Goldenrod, FL 32733
(407) 671-7060

GEORGIA

Agape Village
3711 Agape Village Rd.
Macon, GA 31210
(912) 471-3700
Providing mentally disabled with 50 acre protected place to live, work in greenhouses and enjoy active life with supervision.
See ad on page 14

Annandale Village
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381
Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote well-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta.
See ad on page 63

ILLINOIS

Allendale School
PO Box 1088
Lake Villa, IL 60046
(708) 356-3334
Allendale School is a special education program providing comprehensive services to youths with emotional/behavioral disabilities.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
(618) 457-0371
Residential school designed to meet the academic, social and emotional requirements of adolescents (age 12–21) with learning disabilities.

KANSAS

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 262-8271
Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments, short-term treatment programs, and hearing center services are also offered.
See ad on page 84

KENTUCKY

The Stewart Home School
Box 20
Frankfort KY 40601
(502) 875-4664
Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure.
See ad on page 62

MAINE

Bancroft
Lighthouse Road
Owl's Head, ME 04854
(207) 594-7261
Year-round programs and vacation options for people with developmental disabilities/head injury. *See Bancroft in New Jersey section.*

MARYLAND

The Harbour School
1277 Green Holly Drive
Annapolis, MD 21401
(410) 974-4248
Serves LD & multi-handicapped children ages 5 through 21. Services include counseling, OT, job training & a HS diploma.

MASSACHUSETTS

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523
For children who are severely retarded, multiply disabled. Private, non-profit residential school located in the Berkshires.
See ad on opposite page

Crystal Springs School
38 Narrows Rd. Box 372
Assonet, MA 02702
(508) 644-3101, Ext. 328
Established in 1953, Crystal Springs offers licensed home-like residences; and approved private school; full rehab. program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults, birth–22 yrs.
See ad on page 62

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-5597
Residential school for students who are developmentally disabled and require education or assistance in self-care, community living, adapted communication, mobility training or behavior control due to psychiatric/behavioral, medical or therapeutic needs. An intensive program is available for severe maladaptive or self-injurious behavior.
See ad on page 74

League School of Boston
225 Nevada Street
Newtonville, MA 02160
See ad on page 54

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.
See ad on page 63

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with develop. disabilities, behavior disorders age 3–22. Integrated preschool, inclusion services. staff intensive program., functional activity based curriculum., supported employment in modern school and group homes.
See ad on page 73

New England Villages, Inc.
664 School Street
Pembroke, MA 02359
(617) 293-5461
Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities.
See ad on page 62

St Coletta's of Massachusetts Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02339
(617) 826-6371
See ad on page 62

NEW HAMPSHIRE

Crotched Mountain Rehabilitation Center, Inc.
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311, ext. 235
A comprehensive preparatory school and rehabilitation center providing the best in education, a guided return to the community, access to community

680

Berkshire Meadows

is a private, non-profit year-round residential school for children and adolescents who are severely developmentally delayed and my be multiply disabled.

Like other young people all over the world, residents of Berkshire Meadows are collected by bus to go to school five days a week. In this instance, the "buses" are specially-adapted vans, and "school" – the Learning Center – is where they are taught techniques to help them compensate for their tremendous difficulties, and where their bodies are gently persuaded to move more freely and with greater control.

The Learning Center divides the students into two groups: children, and young adults. The groups work in separate Centers, each focusing on different, graduated skill levels. Class sizes and schedules vary from day to day, to accommodate the particular needs of each student.

In the Vision and Sensory Stimulation Center we address those factors that are seminal to the children's physical and emotional development. While all the senses are addressed, our major emphasis is on sight. In the Light Room we use different types of light to determine which is best for a student with visual deficits, and then work under that light to improve his or her use of vision before gradually incorporating the use of conventional white light. The Visual Stimulation room is designed to increase visual awareness and choice- making, as well as to be downright fun: it is equipped with mirror balls, lighted bubbling water, fiber optics and any number of other visually attractive and stimulating light displays

The Main Room is geared toward stimulating the use of all the senses: there are musical activities and movement to increase auditory awareness; busy boxes, vibration toys and texture boards to improve the sense of touch; and at all times there is social contact and "talk" about what is going on. Outside these three rooms in the spacious "hallways" the students work with brightly-colored therapy balls, gently swinging hammocks, soothing rocking chairs and many other devices that encourage vestibular development.

The Task Center is devoted to cognitive development based on Piaget. The children learn to interact with others, to make choices and to feel themselves to be active participants in their environment. We use toys and tasks to develop memory, awareness of the presence of others, and foresight.

The Applied Functional Skills Center teaches young adults to make use of the techniques they have acquired in other areas. For example, pouring skills can be used for mixing ingredients; stacking and matching skills translate into sorting the laundry. The Center is equipped with a kitchen,a, "company store" and a "hotel suite" so that students might plan for gainful employment as hospital orderlies, custodians or stockroom workers.

Our program for young adults also includes Applied Academics, where the students practice skills that will foster independence: name recognition, the use of money, very basic computer skills, packaging and various vocational skills.

All our students, regardless of their ages, participate in the fifth area of the Learning Center, which is Augmentative Communication. We use Functional Communication as an approach to behavior modification.

At Berkshire Meadows, we work to provide the best care and education that expertise, technology and experience can offer. Our intent is for our students to become more independent, more self-sufficient and empowered, so that they might exercise some control over their destinies.

Gail Charpentier, Exec. Dir.
Berkshire Meadows,
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523)

housing, education, and support services for lifelong planning.
See ad on page 51

NEW JERSEY

Bancroft
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347
State-of-the-art programs in NJ and Maine for children, adults with developmental. disabilities/head injury. Full continuum of educations, vocational and living options. Residential, day and outpatient services. Neuropsychological testing.

Durand Academy, Inc.
230 N. Evergreen Avenue
Woodbury, NJ 08096
(609) 845-0666
Durand Academy provides certified educational programs, residential programs and family support to children age 3 through 21 with autism, emotional disorders and multiple handicaps. The program emphasizes a structured curriculum and social skills development.

ECLC of New Jersey
302 North Franklin Turnpike
Ho-Ho-Kus, NJ 07423
(201) 670-7880

ECLC of New Jersey
21 Lum Avenue
Chatham, NJ 07928
(201) 635-1705
Serving children w/learning disabilities ages 5-21. Program inc. remediation, emotional support, therapies & prevocational act. Campus in Ho-Ho-Kus & Chatham.

NEW YORK

Conductive Education Center of Long Island
248 W Park Avenue/Ste 305
Long Beach, NY 11561
(516) 432-6260
Fax: (516) 889-5154

New York University—Para-Educator Center
One Washington Place
New York, NY 10003
(212) 998-5800
Two year post-high school program for severely learning disabled young adults. Courses & supervised job training in human services, while emphasizing independent living skills. Graduates qualified to work with infants, toddlers, young children or senior citizens.

Pathfinder Village
RR #1/Box 32-A
Edmeston, NY 13335
(607) 965-8377
See ad on page 49

OREGON

Mount Bachelor Academy
246301 E Highway 26
Prineville, OR 97754
(800) 462-3404
Located in the forested wilderness of Central Oregon, Mount Bachelor Academy guides youths 13-18 through a year-round course of emotional growth and college prep. For more info on what experts call "the future of education," call or write.

PENNSYLVANIA

The Devereux Foundation
(800) 345-1292, Ext. 3045
(610) 964-3045 fax
(610) 971-4600
Residential, day and community-based treatment centers nationwide. Comprehensive services to individuals of all ages with emotional disturbances, developmental disabilities, mental retardation, dual diagnosis, autism, and post-head trauma.
See ad on page 25

Elwyn, Inc.
111 Elwyn Road
Elwyn, PA 19063-4699
(610) 891-2000/(800) 345-8111
Est. 1852, offering services from infant to adulthood. Education, rehabilitation, vocational training & placement. Day & residential
See ad on page 48

H.M.S. School for Children with CP
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
See ad on page 70

Martha Lloyd Community Services
190 West Main Street
Troy, PA 16947
(717) 297-2185
Superior quality community living opportunities for men and women with mental retardation. life skills; vocational programs; job opportunities; easy access to community resources; experienced, caring staff; excellent health care; annual fees among nation's lowest.
See ad on page 71

Melmark
Wayland Road
Berwyn, PA 19312
(610) 353-1726
A unique community of alternatives near Valley Forge, Pa. Children/adolescents/ adults receive special ed/adult day programs/ OT/ PT/ speech-language/aquatic/pet/ music therapy/horsemanship. Self-help/ safety skills and community involvement promote a more independent life style.
See ad on page 52

Royer-Greaves School for Blind
118 S Valley Road/PO Box 1007
Paoli, PA 19301-0913
(610) 644-1810
Approved school for blind. Community home for MR (sighted or blind). Adult training center. Respite. Immediate openings.

continued on page 74

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:
1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
244	Academic Therapy	14
245	Agape Village	14
	Apple Computer	60
170	Aquatic Therapy	20
218	Association for Birth Defect Children	8
167	Ballard Medical Products	30
6	Berkshire Meadows	65
173	Bethesda Lutheran Home	74
10	Charles C. Thomas	34
185	Children's Specialized Hospital	56
90	Chrysler	13
186	Civitan International	54
227	Clinician's View	75
11	Columbia Medical	12
12	Columbia Medical	33
109	Consumer Care	28
16	Convaid	23
17	Crotched Mountain	51
151	Crystal Springs	62
18	Cumberland Hospital	29
19	Devereux	25
139	Don Johnston	74
24	Edmark	40
172	Elwyn	48
25	Equipment Shop	24
26	Estate Planning	81
27	Evergreen Center	74
261	Finn Strong Designs	7
29	Flaghouse	24
30	Ford	C2
235	G. Hirsch & Co.	27
36	Haverich Ortho Sport	60
38	Heartspring	84
39	HMS School	70
250	Hospital for Sick Children	24
121	IBM	24
41	Imaginart	20
42	Innovative Products	81
211	Invotek	46
254	ITN	C3
7	J.A. Preston	C4
44	Jay Medical	3
247	Key Concepts	14
46	Kid Kart	15
200	League School	54
15	Marblesoft	81
175	Martha Lloyd	71
252	Medical Claims Processing	59
253	Melmark	52
52	Mulholland	8
248	NAPSEC	70
251	National Head Injury Foundation	45
171	New England Center for Autism	73
55	New England Villages	62
219	Oralgiene	9
161	Pathfinder Village	49
249	Porter Sargent	56
103	Rhamdec	19
214	Richer Life	28
65	RICON	5
66	Rifton	20
232	Rock N' Roll	52
68	Sentient Systems Technology	11
73	St. Coletta (MA)	62
74	St. Coletta (WI)	58
77	Stewart Home School	62
202	Temasek Telephone	56
215	Tommorrow's Child	45
82	TRIAID	81
85	Voorhees Pediatric Facility	20
162	Willow River Farms	56
86	Woodbury Products	49

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

682

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___)_____ Fax(___)_____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month
17❑ three months
18❑ nine months
19❑ one year

Issue Date: September 30, 1994

Expiration Date: December 31, 1994

Oct

1	2	3	4	5	6	7	8	9	1(
11	12	13	14	15	16	17	18	19	2(
21	22	23	24	25	26	27	28	29	3(
31	32	33	34	35	36	37	38	39	4(
41	42	43	44	45	46	47	48	49	5(
51	52	53	54	55	56	57	58	59	6(
61	62	63	64	65	66	67	68	69	7(
71	72	73	74	75	76	77	78	79	8(
81	82	83	84	85	86	87	88	89	9(
91	92	93	94	95	96	97	98	99	10(
101	102	103	104	105	106	107	108	109	11(
111	112	113	114	115	116	117	118	119	12(
121	122	123	124	125	126	127	128	129	13(
131	132	133	134	135	136	137	138	139	14(
141	142	143	144	145	146	147	148	149	15(
151	152	153	154	155	156	157	158	159	16(
161	162	163	164	165	166	167	168	169	17(
171	172	173	174	175	176	177	178	179	18(
181	182	183	184	185	186	187	188	189	19(
191	192	193	194	195	196	197	198	199	20(
201	202	203	204	205	206	207	208	209	21(
211	212	213	214	215	216	217	218	219	22(
221	222	223	224	225	226	227	228	229	23(
231	232	233	234	235	236	237	238	239	24(
241	242	243	244	245	246	247	248	249	25(
251	252	253	254	255	256	257	258	259	26(
261	262	263	264	265	266	267	268	269	27(
271	272	273	274	275	276	277	278	279	28(
281	282	283	284	285	286	287	288	289	29(
291	292	293	294	295	296	297	298	299	30(

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___)_____ Fax(___)_____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month
17❑ three months
18❑ nine months
19❑ one year

Issue Date: September 30, 1994

Expiration Date: December 31, 1994

Oct

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

684

Market Place

Bibs

Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

DISPOSABLE • MOISTURE-PROOF
REUSABLE • PROFESSIONAL QUALITY
Great for Home, Travel, School, Parties and Picnics
coverups
THE SUPER BIBS

100 BIBS DELIVERED $9.95
Available in Continental U.S.A.
30" x 16"
Soft absorbent tissue on front side
Strong, liquid proof plastic backing
Eliminates costly laundering
Easy to put on and take off
Comfortape to wear snug to neck
Full cut for maximum protection
Send to
P.L. CORP.
P.O. Box 2517-C
Holyoke, MA 01041

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Clothing

Richman Cotton Company
100% Cotton Clothing & Blankets
Easy to dress. Easy to see.
FREE Catalog. 800-992-8924.

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical Don't pay retail! Fall savings on all scooters, wheelchairs, ramps and cushions. Free Brochure. (800) 877-9100

Florida

Home Medical Equipment Co.
2137 Fowler Street
Fort Myers, FL 33901
(800) 226-0404
Custom wheelchairs and seating for pediatric to geriatric. On-site repair center. Rental of most medical equipment and vans.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

Maryland

Choice Seating & Rehab
501 North Centre Street
Cumberland, MD 21502
(800) 327-8713 / (301) 722-6300
Serving Western MD, SW PA, and adjacent WVA. Custom W/C, home & van lifts, electric scooters, PT & OT on staff. Sales and service.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Summers Laboratories, Inc.
Collegeville, PA 19426
(800) 533-SKIN (7546)
Triple Paste™ for diaper rash and chronic irritation. Used at leading children's hospitals. Available without prescription. Call now for free treatment information.

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Software

UCLA Microcomputer Project
1000 Veteran Avenue/Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
Catalog of dev. appropriate software for children w/disab. 18 mths-5 yrs. Apple, Mac, IBM, cause/effect, game format, basic preschool concepts

HANDWRITING EXERCISES TO MUSIC

Improve eye-hand and small-muscle coordination

Ages 4-7 $15.95 + $2 s/h
Ages 7-up $19.95 + $2 s/h

To order: CALLIROBICS
P.O.Box 6634 Charlottesville,VA 22906
1-800-769-2891

$2 off with this ad

Toys & Hobbies

TFH (USA) LTD.
4449 Gibsonia Road
Gibsonia, PA 15044
(412) 444-6400
FREE CATALOG! Fun and achievement products for children with special needs. Call or write for more information

Books, Audio/Video & Educational Material

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

To place an ad, contact Barbara Nastro at (201) 680-4874

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- *Physical Therapy*
- *Occupational Therapy*
- *Speech and Language Therapy*
- *Communication Aids*
- *Special Education*
- *Music Therapy*
- *Special Medical Attention*
- *Adapted Recreational Activities*

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

The National Association of Private Schools for Exceptional Children (NAPSEC)

Founded in 1971, NAPSEC is dedicated to promoting excellence in private special educational settings for exceptional children.

NAPSEC
1522 K Street, NW, Suite 1032
Washington, DC 20005
(202) 408-3338
Sherry L. Kolbe, Executive Director

Circle # 248

Made in USA Pat. 5168889

BEAT THE HEAT!

- Comfort for your child
- Peace of mind for you
- Plus, rain protection

The WEATHERBREAKER
Wheelchair/Scooter Canopy

800-795-2392

DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

Providing Comfort to Those Who Want It!

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

West Virginia

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

corrections

Correction to *Manufacturers of Incontinence Products* (August 1994)

G. Hirsch and Company
1525 Adrian Rd.
Burlingame, CA 94010
(800) 638-8800
disposable products, reusable products
See ad on page 27

Direct Delivery Services
Promise Products
PO Box 79603
Houston, TX 77279-9603
(800) 659-8037
disposable products, reusable products, skin care products, deodorizing products, bedwetting products

Directory Additions

When we put together the directory of MANUFACTURERS OF AUGMENTIVE AND ALTERNATIVE COMMUNICATIONS DEVICES that appeared in the May issue, several important manufacturers were inadvertantly omitted. They are:

Adamlab
33500 VanBorn Road
Wayne, MI 48184
(313) 467-1415

gmr Labs
1030 E. El Camino Real #308
Sunnyvale, CA 94087
(408) 985-7200

686

Superior Quality
Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day, residential and vocational programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. **A new community-based program for men has been added.** The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

All Programs Offer These Advantages

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

MARTHA LLOYD COMMUNITY SERVICES

For Information Call

(717) 297-2185

or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947

Circle # 887

WHAT'S HAPPENING

Standing Outside the Fire

Country music star Garth Brooks has made a powerful video portraying a young man with Down syndrome. The video, directed by Jon Small for Brooks' hit song *Standing Outside the Fire*, depicts a young man's desire to compete in a high school track meet despite the skepticism of his father and coach.

Inspired by wife Sandy's volunteer work with the Special Olympics, Brooks chose to illustrate his video with a person eager and determined to participate in all aspects of life. "To me, this song is about passion," Brooks told *Exceptional Parent*, "and one of the most passionate things I've ever seen is an athlete striving to be his or her best in spite of physical or mental challenges. In this video, the parents, in spite of their differences, find a common ground of support for their son and help him turn his dream into a passionate reality."

Country music star Garth Brooks with actor Gerard Fobes during filming of the video for Brooks' hit song STANDING OUTSIDE THE FIRE. *(Photo courtesy of Picture Vision.)*

Gerard Fobes, a 28-year-old California resident, was chosen to play the role of the determined young athlete. Fobes is a former Special Olympian. Other Special Olympic athletes were also part of the filming. Brooks' production company, Picture Vision, made a donation to the Special Olympics for every Special Olympic "extra."

The video can be seen on TNN, CMT, and VH-1.

–*S.W.*

Publications

• *Making the Most of the Law: Education and the Child with Disabilities* is the first comprehensive book on the educational rights of students with disabilities in Canada. The book explains public school acts and regulations of Canadian provinces and territories and explains how to be an effective child advocate. The book costs $20 (Canadian), and can be ordered from the Learning Disabilities Association of Canada, 323 Chapel St., Suite 200, Ottawa, Ontario, Canada K1N7Z2, (613) 235-5391.

• The Candlelighters Childhood Cancer Foundation has published *The Candlelighters Guide to Bone Marrow Transplants in Children*, a book that explains the procedure and answers many commonly-asked questions.

Also available is *Educating the Child with Cancer*. The publication discusses issues of communication between families, school educators and treatment centers; school reentry; cognitive effects; legal rights and siblings.

Single copies of both books are free to parents of children who have cancer; cost to others is $7.50. Candlelighters, 7910 Woodmont Ave., Suite 460, Bethesda MD 20814-3015, (800) 366-2223.

• The Alliance of Genetic Support Groups (AGSG), in cooperation with the March of Dimes, has published an 83-page resource guide on health insurance. The $10 guide can be ordered from AGSG, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815, (800) 336-4363.

• Published by the mother of a child with attention deficit disorder (ADD), *Gregory's World* is a monthly newsletter for parents who have children with ADD. The newsletter includes personal experiences of parents and kids, practical tips and resources. Subscriptions cost $20/year. For a free copy, send a long, self-addressed stamped envelope to *Gregory's World*, 1957 Woodmere Loop, Montgomery, AL 36117.

• *Directions: Technology in Special Education* is a new monthly newsletter for parents and educators of children with disabilities. The newsletter provides technology tips for home instruction, product descriptions and reviews, information on adaptive and assistive technology devices and reports on new Department of Education legislation. Subscriptions cost $9.95/year. Contact DREAMMS for Kids, 2763 Tasha Dr., Clearwater, FL 34621, (813) 781-7711 or through CompuServe at 74631,3675.

• *Stories of the Heart: Inclusion Taking Hold in Connecticut* is a collection of 22 vignettes that describe the building of relationships between children and adults with disabilities and other members of their communities. The booklet costs $4 and can be ordered from Communitas, P.O. Box 374, Manchester, CT 06045, (203) 645-6976.

• *Alternately Speaking* is a quarterly newsletter offering readers information about augmentative and alternative communication (AAC) issues. The publication, produced independently by a user of AAC technology, is available from Augmentative Communication, 1 Surf Way #215, Monterey, CA 93940, (408) 649-3050; $22/year for AAC users or parents of children who use AAC; $30/year for all others.

• The Area Child Amputee Center offers a number of helpful booklets for families and teachers. The three booklets entitled *Children With Limb Loss: A Handbook for Families* are based on three general phases of child development. *Book One* deals with birth to five years; *Book Two* deals with ages six to twelve; and *Book Three* deals with adolescence. Other titles include *Children With Hand Differences: A Guide for Families* and *Children With Limb Loss: A Handbook for Teachers*. Each booklet costs $2, plus postage and handling—75¢ per copy for 1–3 copies; 50¢ per copy for 4–9 copies. Available from Area Child Amputee Center, Mary Free Bed Hospital and Rehabilitation Center, 235 Wealthy St., SE, Grand Rapids, MI 49503, (616) 454-7988.

• The Alexander Graham Bell Association for the Deaf has published a brochure on cochlear implants. The brochure explains how the implant works and describes implant surgery. Single copies are free from Publication Sales Department, A.G. Bell Associa-

688

A recent episode of MISTER ROGERS' NEIGHBORHOOD introduced young viewers to wheelchair basketball. Surrounding Mister Rogers are (from left) Darius Carlins, John Sikora, Leah Hann and Bradley Ramage.

tion, 3417 Volta Pl., NW, Washington, DC 20007-2778, (202) 337-5220 (V/TTY).

• The National Technical Institute for the Deaf has published *New Solutions to Old Problems: Telecommunications for Deaf and Hard-of-Hearing Employees.* It offers a practical overview of telecommunication options for deaf and hard-of-hearing professionals. The booklet costs $2, and can be ordered from R.I.T., Campus Connections Bookstore, 48 Lomb Memorial Dr., Rochester, New York 14623-5604.

Encyclopedia Articles in Braille

Seedlings Braille Books has announced a new free service—*World Encyclopedia* articles in Braille. Seedlings' computers will translate requested articles. Call (800) 777-8552 and give your topic, name, address and phone number. The printout will be mailed to you within five business days. Seedlings is a non-profit corporation dedicated to providing low-cost Braille books for children.

Developmental Delay Survey

The Developmental Delay Registry (DDR) is conducting a survey to determine any apparent cause-and-effect relationships in children diagnosed with severe developmental delays, including autism and pervasive developmental disorder. The survey can be completed in about 10 minutes. The registry hopes to gather information on 1,000 children. If you are interested in participating, contact Patricia S. Lemer, DDR, P.O. Box 12394, Silver Spring, Md. 20908, (301) 924-3060. The survey can be accessed on CompuServe in the ADD Forum, TS/PDD/Autism Library. Names of participants are requested, but not required.

Reader Survey

Early this year, we mailed a survey to some of our subscribers; many responded by telling us about themselves and their families. We were pleased to learn that most of our subscribers read every page of each issue, often spending more than an hour in the process. We also learned that 86 percent save their issues; others pass them along to friends. Our readers also told us that their children are likely to need extra help in self-care, communication, mobility, computer technology and recreation.

We appreciate this feedback, but we remain frustrated by the fact that many parents and professionals do not know about our magazine. Please help us spread the word by sending a note to the acquisitions librarian at your local public library and by encouraging subscriptions among the professionals who are involved with you and your child.

—*S.D.K.*

We Can Make A Difference!

"Now I can see my beautiful daughter flourishing and making progress that I never thought possible! Thank goodness for a place like this school."

–Parent
Intensive Program

When you feel that there isn't any answer, when you feel there are no other options available, **DON'T GIVE UP!** Our Intensive Program makes a difference for students with serious, challenging behaviors. We accept students who require the specialized care that other schools just cannot provide. We give our students state-of-the-art educational and residential programs free of painful aversives and excessive medication.

Many of our students arrive at the New England Center for Autism after having had a long history of rejection and failure. With us they receive intensive, positive, behaviorally oriented treatment that focuses on developing the coping skills and appropriate behaviors which enable them to live and work successfully with minimum support. Intensive Program students participate in the full range of academic, community, and recreational activities provided for all of our students.

*Let **The New England Center for Autism** make a positive difference in your child's life.*

For more information on our Intensive Program, please contact **Catherine M. Welch, MEd, Director of Admissions.**

The New England Center For Autism

The New England Center for Autism
33 Turnpike Road, Southboro, MA 01772
(508) 481-1015
Just 20 miles from Boston

Circle # 171

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle #27

Circle # 27

SCHOOLS, COLLEGES, & RESIDENCES

SOUTH CAROLINA

Trident Academy
1455 Wakendaw Road
Mt. Pleasant, SC 29464
(803) 884-7046
Boarding and day students with learning disabilities in grades K5-12. A structured individualized learning environment.

SOUTH DAKOTA

Children's Care Hospital and School
2501 W 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840/(800) 584-9294
A private, non-profit facility with outreach, outpatient, day school and residential services for children from birth through age 21 who have disabilities or chronic illnesses. Our multi-disciplinary teams provide family-centered services based on each child's needs.

TEXAS

Willow River Farms
PO Box 450, San Felipe, TX 77473
(409) 885-4121
Organic farming & artisan community meeting the special needs of adult men & women with mental retardation. Beautiful rural atmosphere.
See ad on page 56

VIRGINIA

Faith Mission Home
HCR 1 Box 114
Free Union, VA 22940
(804) 985-2294
Res. care and training center for ambulatory MR or brain-injured children and young adults located in Blue Ridge Mountains.

WISCONSIN

Chileda Habilitation Institute
1020 Mississippi Street
La Crosse, WI 54601
(608) 782-6480
Fax (608) 782-6481
Residential treatment for youths with severe mental & physical disabilities, closed head injuries & challenging behaviors.
See ad on page 63

St. Coletta School
W4955 Highway 18
Jefferson, WI 53549
(414) 674-4330
Year-round res. program. in academic instruction and pre-vocational training for MR/DD. Adult res. facility. Long term opportunity for care.
See ad on page 58

Did I Hear You Say Help?

National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

- ☐ Are you looking for appropriate services for yourself, your family member or client?
- ☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline 1-800-369-INFO.

We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle # 173

Conversation Software for Real Communication

Talk:About™
AAC solution for your Macintosh®
New Era for Non-Speaking Persons

- conversation foundation
- fast & efficient
- share opinions and stories

DON JOHNSTON
800.999.4660 USA CANADA
708.526.2682 USA GLOBAL

Call for a demonstration disk

Discover Potential... Experience Success

Circle # 139

690

Clinician's View

Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices.The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays,

by Susanne R. Hays, M.S.,R.N.,C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. **ED 077OD**

Effective Intervention For Self-Feeding Success,

by Christine A. Nelson, Ph.D.,OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. **ED 078OD**

Massage For The Infant With Developmental Disabilities,

by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant's individual concerns. A valued resource for every parent to assist their child's development.

ED 079DD

Near Normal Feeding For Infants With Oral-Facial Anomalies,

by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant's born with cleft lip and/or palate can be very difficult.Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies that parents can follow. **ED 080OD**

Mail to: **Exceptional Parent,** Dept. EP9409, P.O. Box 8045, Brick, NJ 08723
Or call **1-(800) 535-1910**

QTY	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item, 75¢ for each additional item. Foreign – $6.50 for 1 item, 75¢ for each additional item.

Sub-Total	
N.J. Res 6% tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: Visa Mastercard

Account Number: _____ Exp. Date: _____

Signature _____

U.S. funds only. Those prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

691

Circle # 227

NEW PRODUCTS

INFANT MAZE

The Infant Maze is a freestanding playground that can be used by infants six to 18 months of age, with or without disabilities. This compact system includes interactive activity panels with aluminum handles to encourage mobility, stimulate the senses and develope physical skills.
Landscape Structures, Inc., Delano, MN 55328.

Circle # 255

SPECIALTY SEATING SYSTEMS

Kids can use this adjustable seating and table system in therapeutic, educational and home environments. Back adjustment, tilt in space, seat pan adjustments, adjustable leg heights, adjustable pommel and a lap belt are standard chair features. Optional features include a shoulder harness, feeding tray and seat cushions.
Designabilities, Inc., Millbury, MA 01527.

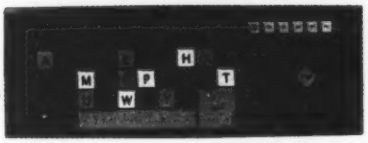
Circle # 256

GUS! MULTIMEDIA SPEECH SYSTEM FOR WINDOWS

This multimedia augmentative communication device features access to mainstream software applications; customized buttons; CD-quality sound, including sound effects and music; user-defined symbols; switch/scanning; a mouse which may be used as a switch interface and built-in programs. This state-of-the-art system is designed to evolve along with the user's abilities and education. There is no limit to the number of screen layers the user may develop. For DOS-based computers with Microsoft Windows version 3.1 or later and a Sound Blaster-compatible sound device.
Gus! Communications Inc., Richmond, British Columbia V7C 2G6.

Circle # 257

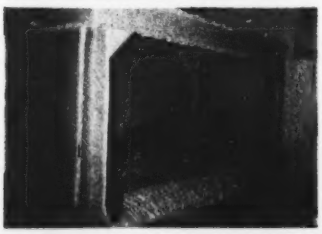
KID KEYS



Little fingers sometimes need bigger targets; Kid Keys provides them. This keyboard for preschool- and primary-school-aged children has one-inch-square letter and number keys and a two-inch-square return key. Letters are arranged alphabetically to reinforce learning the alphabet. Bright colors and large labels also help children to distinguish the keys. No special software is needed to use the keyboard, which is compatible with PC/AT 386 or 486 computers.
Greystone Digital, Huntersville, NC 28078.

Circle # 258

THE VAIL 2000 ENCLOSED BED



For children who require a restrained environment, this movable unit—complete with a mattress, frame, canopy cover, border, pads and covers—may be used to provide a protected perimeter while still allowing the child free movement and visibility of his or her surroundings. The head of the bed can be raised and lowered, and all removable components are machine-washable. The borders and skirts come in a variety of bright colors and patterns.
Vail Products, Inc., Toledo, OH 43605.

Circle # 259

PROTOCOL-CE

The Protocol-CE is the answer for wheelchair users interested in working in clean rooms, laboratories and sterile work areas. Already in use in the semiconductor industry, this manual wheelchair with one-piece construction, coated frame and low-contamination bearings is ideal for science students or young adults who wish to work in controlled environments. All components of the chair are designed to be resistant to corrosives, cleaning agents and contamination. Each chair is individually inspected, cleaned and double-bagged prior to shipping. A specially-designed clean room garment is also available.
Forth Research, Inc., Scottsdale, AZ 85257.

Circle # 260

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

692

CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

Child Care:
Who Cares for the Children with Chronic Illness and Disability?

Historically, child care (or daycare) has been treated very differently than education. While schools are mandated to provide educational programming for children with special health care needs, parents are responsible for providing daycare.

So what happens when children from birth to three-years-old need early intervention services?

That's one of the questions researcher, Lynne M. Lent, set out to answer in her regional study of "Child Care for Children with Special Needs from Birth to Three Years." She found mounting evidence that early intervention appears to be most effective when it is:

- part of a child's daily routine, and
- when the family's basic needs are met.

What she found is, regardless of the potential effectiveness, child care is seldom included in early intervention services.

Like most parents in the U.S. today, child care is a critical issue for

Child Care
Turn to page 78

INSIDE

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with *Exceptional Parent* to publish *Children's Health Notes* to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.

DEFINITION

Child care, including all forms of daycare, is provided by child care professionals, family members or friends of the family, and may occur in family daycare homes, child care centers, or nursery schools with or without extended daycare.

PHOTO BY DIANE HOVEY

693

Children's Health Notes

MANAGING EDITOR
Peggy Mann Rinehart

PRODUCTION/
EDITORIAL ASSISTANT
Linda Pratt

STAFF:
Center for Children with Chronic Illness and Disability
Robert Wm. Blum, M.D., Ph.D., Director; Joan Patterson, Ph.D., Director of Research; Peter Blasco, M.D., Director of Education; Harriet Kohen, M.A., Center Coordinator; Pat Faulkner, Field Coordinator; Peggy Mann Rinehart, Director of Communications; Nancy Okinow, M.S.W., Parent & Policy Coordinator; Karen Stutelberg, Administrator; Clara Wolman, Ph.D., Research Coordinator; Sandra Kothe, Center Secretary.

***Children's Health Notes** is published periodically and is made possible through Grant H133B90012 from the National Institute on Disability and Rehabilitation Research. The opinions expressed do not necessarily reflect the views of the University of Minnesota or its funding sources.*

Children's Health Notes
Box 721
420 Delaware St. SE
Minneapolis, MN 55455
(612) 626-4032 V
(612) 624-3939 TDD

PHOTO BY DIANE HOVEY

Child Care
From page 77

families with children who have special health care needs, and it may be even tougher to find. However, it appears that the benefits of placing children with chronic illness or disabilities into the least restrictive child care setting far outweigh the barriers. Lent reports one success story:

Amy is a bright, active child who was born two months prematurely and diagnosed with cerebral palsy and seizures. Her child care providers remember that, when Amy started child care, her physical therapists came to the center and provided instruction about appropriate exercises and activities. "Open communication and commitment from everyone—parents, teachers, therapists and even the bus driver—made this a very successful experience," the care provider explained. Today, Amy, a high school student, works as an assistant at that same child care setting. She is bright, enthusiastic, and is great with young children.

There is no doubt, when parents and child care providers are committed to including all children in daycare, everyone wins.

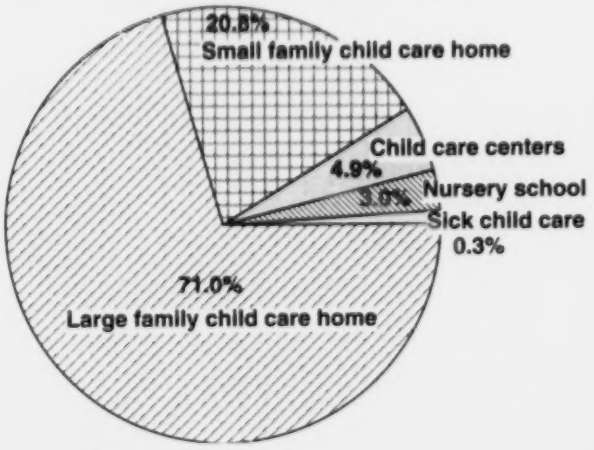
Providers respond to questionnaire

Many providers said they believe that having children with special needs had a positive effect on all the children enrolled in daycare. They believe having children with special needs helped both children and adults to accept differences among people.

Still, more than one-third who responded to Lent's survey believe that the needs of children with chronic conditions caused the other children to be "short-changed." Some reported that

Child Care
Turn to page 79

Where do they go for child care?



694

Child Care
From page 78

parents withdrew their able-bodied children from the child care program. Some expressed concern about behavior problems. Still some did not know how to keep children from making fun of the child with disabilities.

Clearly, the perceived barriers to providing care for children with chronic illness or disability could be improved through training; however, currently, most training of providers is done by the family. Lent's summary calls for including child care providers in the IFSP (Individual Family Service Plan) loop.

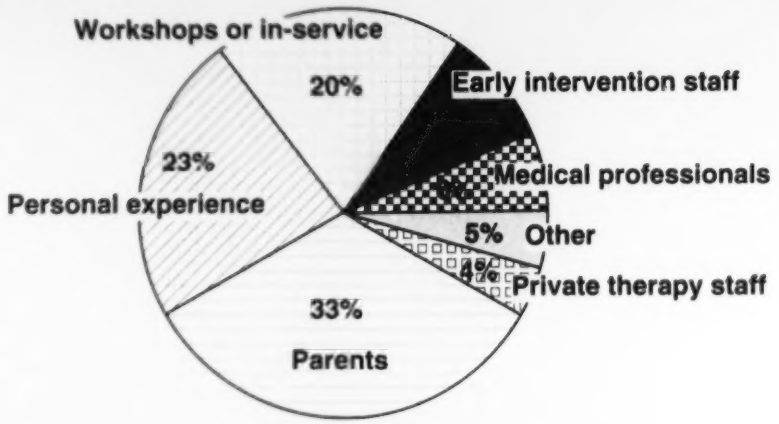
When asked, those who provide child care to families with children who have chronic illness or disability say they are often left out of the development of Individual Family Service Plans (IFSP).

When asked, the same providers would like to be a part of the planning team and would like be trained to work with children with special needs.

Lent sent surveys to 1,014 licensed providers in one metropolitan county in Minnesota; she received 304 responses.

She asked providers 21 questions that included descriptions of the child care setting, services provided to children with special needs, participation in the IFSP process, communication and overall satisfaction. She also asked for recommendations to improve a provider's ability to service children with special needs.

Who trains child care providers?



Parents Respond

Parents of children with special needs who responded to this survey preferred small and large family daycare to center-based daycare. By and large, they found providers through the grapevine rather than using child care resource and referral services.

Families report that the type and severity of their child's condition had little to do with the success of, or disenchantment with, child care. Rather, they credit communication and commitment. When child care providers are committed to including a child with special needs into their program, and when they communicate with all the parents and children in the program, and when the program is made convenient, they are successful. Lent surveyed parents of children enrolled for at least two months in an early intervention program for children from birth to three years. Forty nine (of 180 surveys sent) were returned.

What Can Be Done?

Clearly, daycare and early intervention need to be linked. One way is for families to ask their daycare providers to attend the IFSP meetings along with the rest of the team.

In addition, all states accepting Part H funding are required to form state- and community-level interagency councils. These are formed in many different ways. In Minnesota, for example, there is a Governor's Coordinating Council on Early Childhood Intervention. Councils like these should include not only publicly-funded programs like Head Start, but private child care agencies.

Child Care
Turn to page 80

RESEARCHER

Lynne M. Lent, OTR, is an occupational therapist finishing a masters degree in the School of Public Health at the University of Minnesota. The material written here is based on her paper, *Child Care for Children with Special Needs from Birth to Three Years*. Copies of the complete study are available in hard copy or on disk: Specify either Microsoft Word for Macintosh or Word Perfect for PCs. Please send your request and $10.00 to Peggy Mann Rinehart, Director of Communications, Center for Children with Chronic Illness and Disability-CHN, Box 721, University of Minnesota, 420 Delaware St. S.E., Minneapolis, MN 55455.

695

Provider, Family and Early Intervention:

A Working Together Checklist

Here's a checklist of questions that parents with children who have chronic illness or disabilities can use when working with their child care providers and early intervention staff. Use this to help formalize the roles and responsibilities of each person involved in providing child care.

✓ How do the family and the child care provider communicate?

Some families like to use notebooks that go back and forth to the child care provider. Others prefer brief daily conversations and weekly or biweekly conferences.

✓ What happens when something goes wrong?

Some families write instructions for the child care provider in case of an emergency. This can include what to do in the event of a seizure to more complicated events. It can detail which doctor to call, how to transport the child, which medications to give, and how to contact the parents. Some families rent or buy "beepers" so they can be easily contacted in the event of an emergency.

✓ How do the child care provider and early intervention team (including therapists, social workers, and others) communicate?

You might want to ask your child care provider to become a member of the early intervention team.

✓ Who teaches the child care provider about the needs of the child?

Are there video tapes available from your local or regional parent training program or from condition-specific organizations like the Epilepsy Foundation? Can your child care provider attend continuing education programs along with other early intervention specialists?

✓ How will any extra cost of providing care be covered?

Many child care providers are concerned that the staff-to-child ratios needed to stay in business reduce their ability to include children with special health care needs into child care programs. Check with your county social worker or early intervention coordinator to see if there are any funds available through your state or county to assist your child care provider in making modifications.

What Happens Next?

Child care is still a "parent" driven issue. Here are some recommendations that will increase the inclusion of young children into child care:

- Explore ways to include child care providers into the IFSP.
- Encourage early intervention personnel to provide consultation and technical assistance to child care providers.
- Teach IFSP team members collaboration skills.
- Develop programs that assist families in locating and selecting quality programs.
- Provide pre-service and in-service training programs for child care providers.
- Develop more equitable funding for child care programs that include children with chronic illness and disability.

Child Care
From page 79

Fourteen national early childhood organizations have formed "LINKS," Linking Networks for Kids to promote comprehensive services and supports for developmentally vulnerable young children and their families. They hope to:

- increase knowledge, awareness, and availability of critical resources and programs;
- identify and disseminate successful strategies for using those programs;
- inform government administrators, planners and policymakers; and
- promote policy changes at the federal, state and community levels.

The **Center for Children with Chronic Illness and Disability** was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

696

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle # 26

5 Models Available Now

BIGFOOT

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Bigfoot 4 X 4 Inc. St. Louis, MO

Circle # 42

Obviously, a computer program can't take the place of a good teacher. But the Early Learning series from Marblesoft is a tool that helps teachers keep learning fun for early elementary and special education students.

The software is easy to use -- for both the student and the teacher. And when used with a speech synthesizer, there's the added advantage of a human-sounding voice that praises right answers and gently encourages the student after wrong ones.

For more information and a complete product catalog, please call (612) 755-1402.

MARBLESOFT

12301 Central Ave. N.E. Blaine, MN 55434

Circle # 15

TRIAID
REHABILITATION PRODUCTS

Picture Of Fun!

The best Europe has to offer at American prices. Three different styles in various sizes for all ages. Call or send for our new color catalog.

VISA-MasterCard Now Available
CALL TOLL FREE 1-800-306-6777
P.O. Box 1364 Cumberland, Maryland 21502 • 301-759-3525

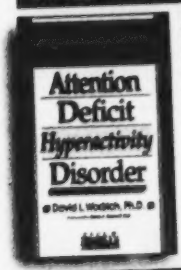
Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle # 82

EXCEPTIONAL PARENT *Library*

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION DEFICIT DISORDER



ATTENTION DEFICIT HYPERACTIVITY DISORDER: *What Every Parent Wants to Know*
D. WODRICH
Prepares parents for at home and at school, empowers and reaffirms parents of their role.
PB070AD **$19.95**

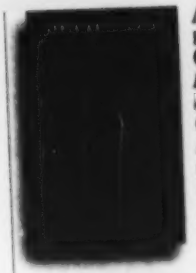
AUTISM

OUT OF SILENCE
a journey into language
RUSSELL MARTIN
A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.
HH083AM **$22.50**

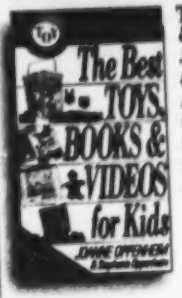
REACHING THE AUTISTIC CHILD
MARTIN KOZLOFF
Focuses on a parent training program that shows how to improve the environment of the autistic child.
BL063OD **$14.95**

EDUCATION

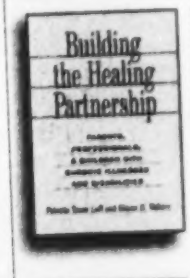
ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
BY TONI FLOWERS
Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels.
PE035OD **$29.00**



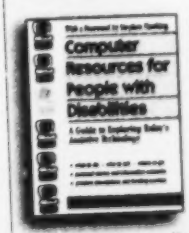
ADAPTIVE PLAY FOR SPECIAL NEEDS CHILDREN: *Strategies to Enhance Communications and Learning*
CAROLINE RAMSEY MUSSELWHITE
A book for parents and professionals summarizing recent advances in using play as a learning tool.
PE042OD **$27.00**



THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
HC082OD **$12.00**



BUILDING THE HEALING PARTNERSHIP: *Parents, Professionals & Children with Chronic Illnesses and Disabilities*
PATRICIA T. LEFF
BL057OD **cloth: $34.95**
paperback: $24.95



COMPUTER RESOURCES FOR PEOPLE WITH DISABILITES: *A Guide to Exploring Today's Assistive Technology*
THE ALLIANCE FOR TECHNOLOGY ACCESS
This book will show you how today's technology is redefining human potential and what it is like to have a disability. It provides user-friendly support, information, and up-to-date answers.
HP087OD **$14.95**

DECIPHERING THE SYSTEM: *A Guide for Families of Young Children with Disabilities*
PAULA J. BECKMAN
Informs parents of children (0–5) of their rights.
BL058OD **$21.95**

DORMAC EASY ENGLISH DICTIONARY
BY DOROTHEE BAKER AND CONSTANCE BETTINO
Containing 5,000 entries, invaluable to elementary and intermediate students with a reading level of approximately 1.0–4.0.
PE033EM paper $19.00
PE033 cloth $29.00

THE EARLY INTERVENTION DICTIONARY
A Multi-disciplinary Guide to Terminology
JEANINE COLEMAN, M.ED.
Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.
WB030EI **$16.95**

THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
WB020OD **$14.95**

NEGOTIATING THE SPECIAL EDUCATION MAZE: *A Guide for Parents and Teachers, 2nd Edition*
ANDERSON, CHITWOOD, & HAYDEN
Easy-to-follow guide to the special education system, demystifies the system—beginning with the very first evaluation through the design of the IEP.
WB019OD **$14.95**

SIBSHOPS
Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PS086OD **$32.00**

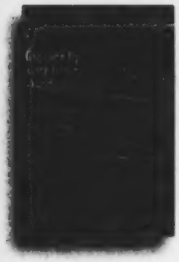
TEACHING THE INFANT WITH DOWN SYNDROME
A Guide for Parents and Professionals
MARCI HANSON
Expanded thoroughly updated, written specifically for the parent of a Down syndrome infants, step-by-step guide.
PE048OS **$27.00**

TEACHING THE YOUNG CHILD WITH MOTOR DELAYS: *A Guide for Parents and Professionals*
M. HANSON & S. HARRIS
Provides information to parents on how motor development influences other areas of development.
PE049PD **$27.00**

TROUBLE WITH SCHOOL
A Family Story About Learning Disabilities
ALLISON & KATHRYN DUNN
Book takes a clear look at the warning signs and common problems associated with LD.
WB028LD **$9.95**

YOU, YOUR CHILD AND "SPECIAL" EDUCATION
A Guide to Making the System Work
BARBARA COYNE CUTLER
Shows parents how to obtain the educational services their child rightfully deserves.
PB0530D **$22.00**

DISABILITY, GENERAL



COUNT US IN
Growing Up with Down Syndrome
J. KINGSLEY & M. LEVITZ
The authors share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship.
HB073DS **$9.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services.***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**

HONOR THY SON
A novel by Edgar Award winner Lou Shaw
This unforgettable story combines suspense, terror and international intrigue—and a father & a son each pursuing a dream.
AB081OD **$12.95**

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals
EP001EP **$14.95**

NOBODY'S PERFECT
Living & Growing with Children Who Have Special Needs
NANCY B. MILLER
Offers parents the strategies and emotional support to create a harmonious daily life and improved communication with family, relatives and professionals.
PB052OD **$21.00**

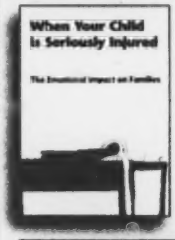
PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

PLANNING FOR THE FUTURE:
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP024OD **$24.95**

WORKING TOGETHER:
Workplace Culture, Supported Employment and Persons with Disabilities
DAVID HAGNER
Assisting individuals to achieve meaningful careers.
BL060OD **$24.95**

INJURY

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$7.50**



WHEN YOUR CHILD IS SERIOUSLY INJURED:
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$4.50**

RELIGION

THAT ALL MAY WORSHIP
An Interfaith Welcome to People with Disabilities
GINNY THORNBURGH
An interfaith handbook to assist congregations in welcoming people with disabilities to promote acceptance and full participation.
ND084OD **$10.00**

Mail to: **Exceptional Parent,** Dept. EP9409, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date ____/____

Signature _____

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

You can see the delight in Rebecca's eyes. When she answers a math question in her fifth-grade classroom...or creates art to hang in the halls of her school...or sings with the choir in a program at City Hall...she enjoys discovering her world.

Rebecca was eight when she arrived at Heartspring. She was unable to express herself...uncontrollable in her home...and uncooperative with her teachers. She was making no progress in a regular classroom, but her parents were reluctant to see their daughter assigned to one-on-one programming. Today, thanks to a program designed to meet this special child's needs, Rebecca is a happier little girl.

At Heartspring, a caring team of specialists takes the time to discover each child. Together with the parents, they develop an individual education plan (IEP) to fit the child's needs.

For some, the program involves full inclusion in a regular classroom. For others, the answer is self-contained programming. And, for many — as is the case with Rebecca — the best program is a combination of the two. Our goal is to provide services that help each child return home as soon as possible.

If we can help your child discover the world, call us.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800- 835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

MAKING INCLUSION WORK *continued from page 46*

Angela's strengths, gifts and talents. People described Angela as "courageous, a pioneer, someone who knows how to make you feel better when you are down, a good bike rider and a ballet dancer."

Finally, the group discussed plans for the summer and upcoming school year—Brownie camp, maintaining relationships with distant relatives, open communication among staff and parents. Circle members thought about ways to help to make these plans succeed, and committed themselves to providing support.

Angela's peers thought it was very important that Angela be allowed to go to the neighborhood playground with her friends, but *without* her mom. One of Vicki's ideas was to start a homework circle in the fall where small groups of children work on assignments together. She obtained the support of other parents to put this idea into action. Angela's circle will meet again in September.

"One of the Gang"

Mrs. Brown, Angela's teacher, recently summed up the year's achievements. "Angela can follow classroom routines with more independence," Mrs. Brown says proudly. "She views her work time as an important part of the school day. She takes turns and shares. She pays attention to stories and group activities for longer periods of time. She can write her own sentences by sounding out words. And most of all, she's one of the gang!"

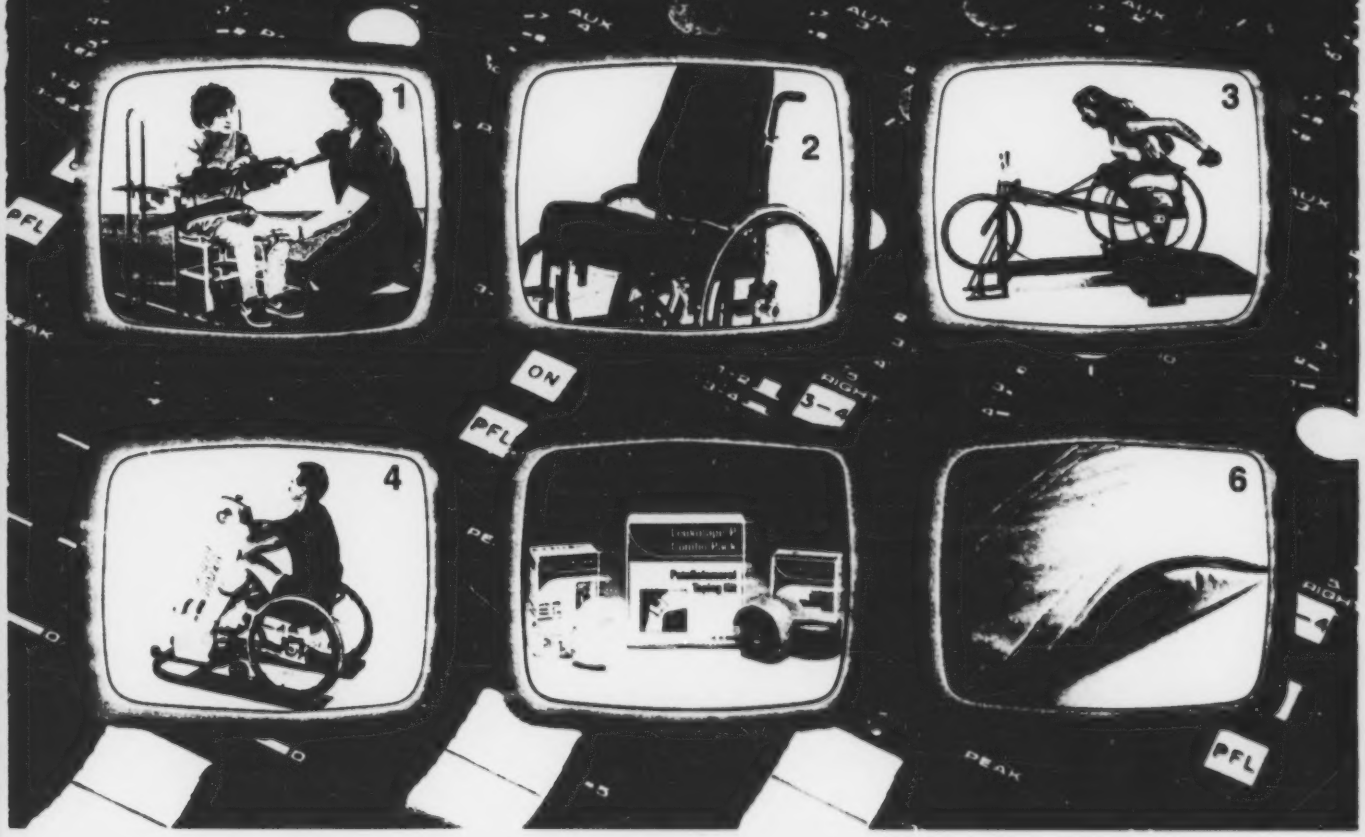
Angela Hart is now a third-grader at School One in the Scotch Plains-Fanwood School District in New Jersey. She has been included in her neighborhood school throughout her entire school career.

ALL CHILDREN BELONG is a collaborative program of the National Parent Network on Disabilities in Washington, DC, and the Statewide Parent Advocacy Network (SPAN) in New Jersey. Support for ALL CHILDREN BELONG is provided by the DeWitt-Wallace-Readers Digest Fund. For more information, call NPND (703-684-6763) or SPAN (908-654-7726).

700

The Cutting Edge Medical Report

The television magazine exploring the latest in healthcare.



"If it's on the cutting edge of tomorrow, we'll bring it to you today."

You are invited to explore the challenges and advancements in healthcare on *The Cutting Edge Medical Report*. Discover organizations that offer innovative services and outstanding products that meet the emerging needs of the physically challenged.

For information on *The Cutting Edge Medical Report*, contact the Information Television Network at (407) 997-5433. Don't miss this sensational new TV show! Consult your local TV listings.

For Information

1. Rifton 914-658-8799
2. Special Health Systems 905-841-1032
3. Top End 800-532-8677
4. Sinties Scientific 918-254-7395
5. Beiersdorf Medical 203-853-8008
6. Patient Guard 800-784-8273

Circle # 254

Quick Change

© 1994 BISSELL Healthcare Corporation J2033

Imagine an infant stander so adaptable it can change its appearance instantly to become a stroller or even a highchair. Tumble Forms®, a leader in early intervention products, now introduces the Chameleon™.

Perfect for home or school use, the Chameleon accommodates children from 25 to 37 inches and up to 50 lbs. With this one lightweight unit, you can create numerous vertical, prone, and supine positions, for sitting, lying, or standing. The seat, seat back, and foot support each adjust for infinite possibilities. Meanwhile, the child is cradled against cushioned supports to ensure proper body alignment. You get three versatile products – stander, stroller and highchair – all for the price of one.

The Chameleon features a removable tray to allow easy transfer as well as swivel casters for portability. Breathable fabric covers are conveniently removed for laundering.

Leave it to Tumble Forms to change the way you view standers.

For more information, call 1-800-631-7277. In Canada call 1-800-665-9200.

Chameleon™ by Tumble Forms®

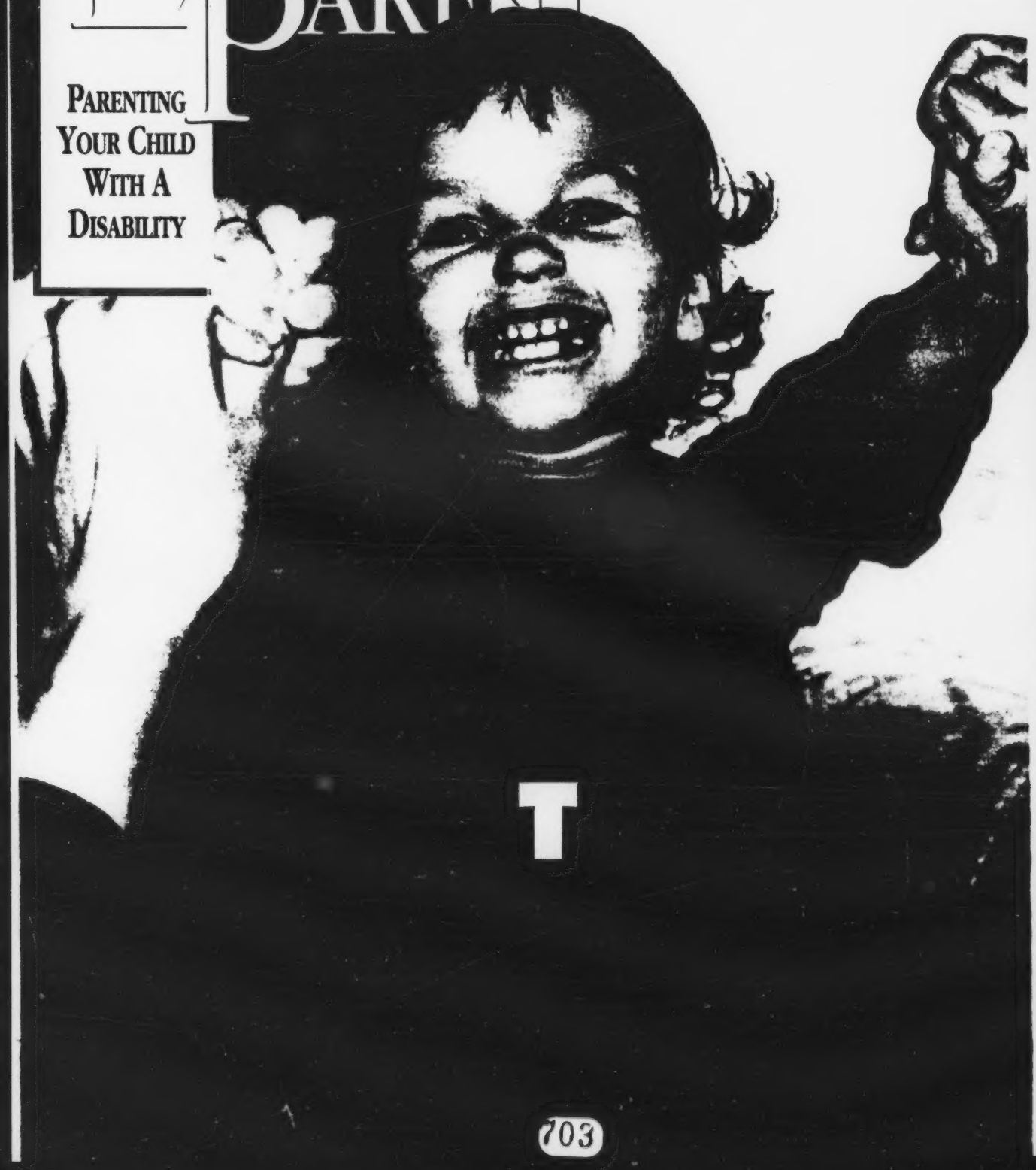
702

Circle # 7

OCTOBER 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY



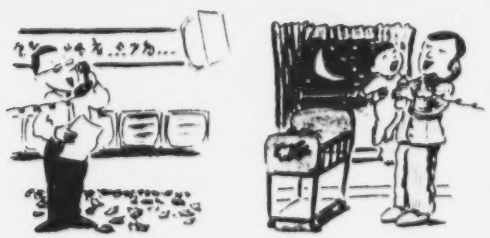
T

703

How easy is it to call from anywhere with AT&T Long Distance Relay Service?

This easy: 1 800 855-2880 (TTY)

Anyone. Anytime. Anywhere. One easy number makes it easy to place long distance relay calls...from any state...to any other state—or even another country...anytime day or night. And with AT&T True USA℠ Savings, it's easy to save money too. When you spend as little as $10 a month on AT&T Long Distance calls, you can save enough to make a difference in your phone bill.* At AT&T, we're dedicated to making phone calls easy for anyone. Anytime. Anywhere.



1 800 855-2881 (Voice) • 1 800 855-2882 (ASCII) • 1 800 855-2883 (Telebraille)

*For more information or enrollment, call 1 800 833-3232 (TTY).

AT&T

704

Circle # 2

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

OCTOBER 1994
VOL. 24, ISSUE 10

PAGE 33

COVER:
Marie Blanchard, 18 months, shows off a winning smile while playing with her grandparents, Ann and Bill Dunne, and cousins at a family reunion last summer. Marie, who lives in Portland, Oregon, has cerebral palsy. Her mother's story about coming to terms with Marie's disability begins on page 26.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005.

All rights reserved, Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation.

POSTMASTER: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

Grieving a Dream by Susan Blanchard 26
A grief ritual is shared with other parents.

Friends Who Care by Sara Brewster 33
Teaching all children about disabilities.

Sibling Concerns by Donald J. Meyer 53
Siblings have special needs, too.

Step By Step by Eleanor Smith 59
Creating no-step entrances.

Dental Care for Children with Disabilities by Steven P. Perlman 62
PART THREE: A visit to the dentist.

TOYS

Toys For Every Child by Marilyn Hammond 36
Choosing and adapting appropriate toys.

Forrest Pumps by Jean Isaacs 40
Forrest's mom finds a water gun that works without adaptations.

Using Ordinary Toys for Kids with Special Needs by Joanne and Stephanie Oppenheim 42

Lekotek Puts Possibilities into Play by Julie Morse and Wayne B. Smith 46

New Products: Toys 52

DEPARTMENTS

Editor's Desk 2
Letters 4
Search & Respond 8
Familiar Faces 14
Ask the Doctor: IRRITABILITY 16
Health Insurance Troubleshooter: FUNDING POWER WHEELCHAIRS 20
Role Models: HARILYN ROUSSO 23
Fathers' Voices: THE BIGGEST GAME by Bill Abbott 55
Directory of Advertisers 66
What's Happening 73
Informational Forum: Networking 77
New Products 80
Exceptional Parent Library 82
Children's Page: MY NEW BROTHER by Bryan Welch 84

EDITOR'S DESK

All children enjoy toys. By their excitement about toys, games and play, children with disabilities clearly remind us that, first and foremost, they are children. Parents may be overwhelmed when selecting toys their children will enjoy because there are so many to choose from, family budgets are limited or a child has unique needs and may not be able to enjoy off-the-shelf toys and games.

STANLEY D. KLEIN, PH.D.

This issue features a special section on choosing toys for children with disabilities. In "Toys For Every Child," Marilyn Hammond describes principles for choosing toys, along with ideas for adaptations. In "Forrest Pumps," Jean Isaacs shares her efforts to adapt toys for her son's use, and her excitement at discovering an off-the-shelf water gun that allowed him to shoot straight!

In the quarterly *Oppenheim Toy Portfolio Newsletter*, Joanne and Stephanie Oppenheim evaluate products for children. Each year, they publish *The Best Toys, Books & Videos for Kids*. Portions from a chapter of that book, "Using Ordinary Toys for Kids with Special Needs," have been adapted for this issue.

Grieving

The emotions parents experience after learning their child has a disability has been described as a mourning process—mourning the loss of the "perfect" child of their dreams. Understanding that this is a normal human reaction has helped parents deal with its many variations. But until I read "Grieving a Dream," I had never seen an article that described in practical terms how a parent, with the help of others, can facilitate this process.

Teaching About Disabilities

In our education issue (September), we did not address disability awareness programs for children without disabilities. In this issue, we report on "Friends Who Care," a national program that helps children learn to respect differences and reach out to one another. We are very interested in learning about other, similar programs.

Reader Participation

In the months since our first *Familiar Faces* page appeared, reader response has been extraordinary. We enjoy receiving your photos and accompanying letters. And although parents tend to take fewer photos as children get older, we would like to receive more photos of older children.

Beginning with this issue, we want to encourage a new kind of reader participation. In each issue, we will ask for reader input about a topic we plan to cover in a future issue. Readers now can have an even more active role in editorial development. See page 8 for our first request.

Health Care Reform and Elections

It has been disappointing and frustrating that, as we go to press, health care reform remains an unfulfilled dream. Now, all candidates for Congress must be informed about how the health care needs of children with disabilities often are short-changed.

An Apology

In the list of Honorable Mentions of the 1994 Educational Program Awards in September, one program was listed incompletely. We regret this production error and apologize to the Weight Conditioning Program at Trenton High School in Trenton, New Jersey.

Special Thanks

Valerie Steele, a dedicated *Exceptional Parent* staff person for many years, has decided to move on. We will miss her friendly spirit and readiness to do whatever is needed. We wish her well.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology, New England College of Optometry

ASSISTANT EDITOR Kim Schive

EDITORIAL STAFF
Marc S. Malkin Valerie Steele

EDITORIAL INTERNS
Jennifer Fisher Ludmilla Panza
Sara Wood Pyongson Yim

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Sutera

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferrante

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (CO, IN, KS, MN, ND, So OH, SD, UT, WI)
Anthony Arnone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, MI, MO, NB, No OH)
John Maisel
(708) 416-0780 Fax (708) 416-0793

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
William Hague
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESIDENCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

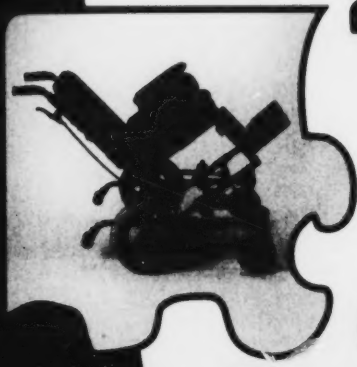
For subscription and advertising information, see page 66. BPA International Consumer Magazine Membership Applied for August 1993.

706

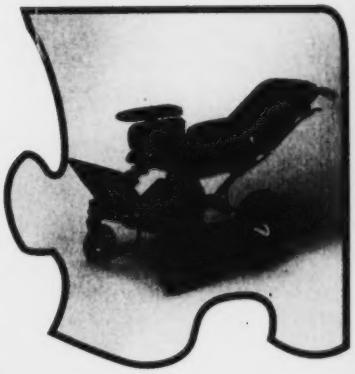
Freedom Designs, Inc.

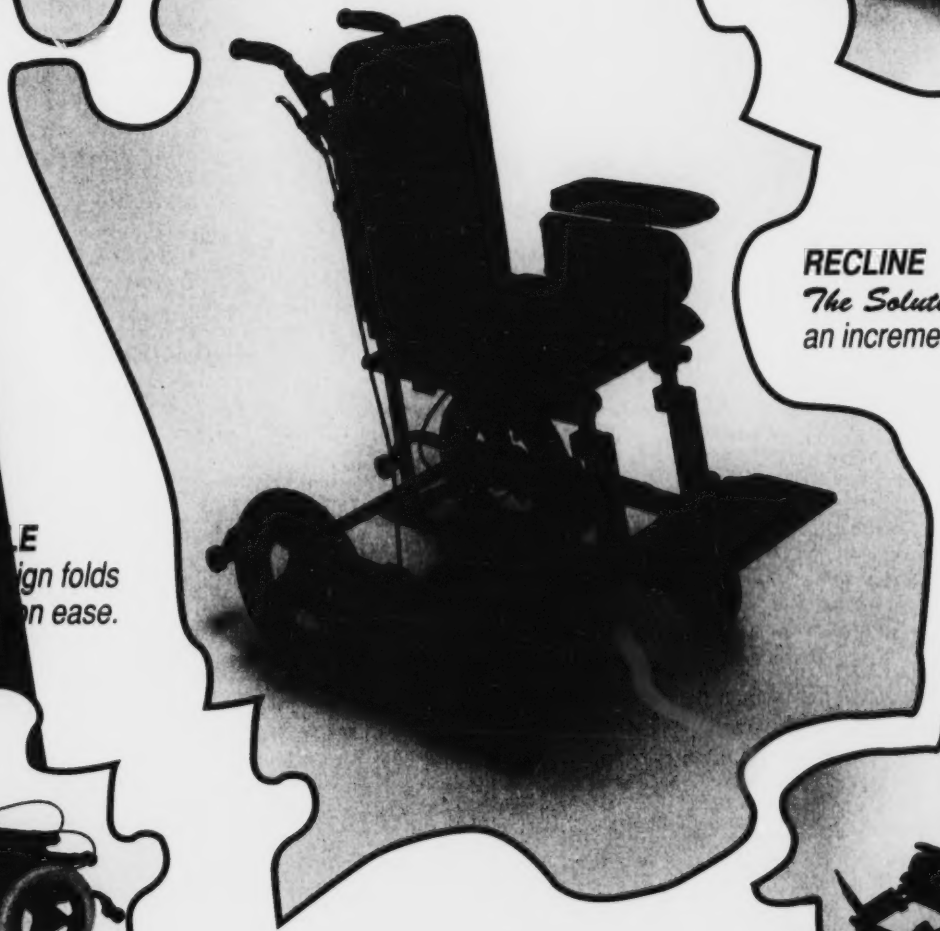
Not just another piece of the puzzle.

The Solution



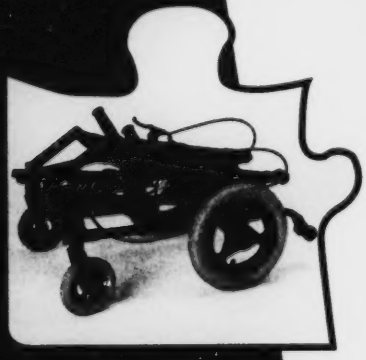
TILT IN SPACE
Our tilt in space feature is easy to operate.

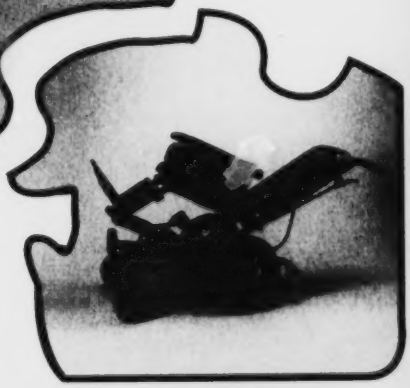




RECLINE
The Solution *offers an incremental recline.*

E
ign folds
n ease.





TILT AND RECLINE
The frame can be reclined and tilted simultaneously.

om Designs, Inc. 2241 Madera Road ◆ Simi Valley, CA 93065
one (800) 331-8551 ◆ (805) 582-0077 ◆ Fax (805) 582-1509

FREEDOM DESIGNS INCORPORATED

Circle # 31

LETTERS

Priests with Disabilities

I was very interested to read about the early childhood and educational experiences of John Kemp (*Role Models*, July 1994). What insight his advocate/father had to promote inclusion from the same perspective with which it is encouraged today.

The unfortunate rejection of John's boyhood interest in the priesthood calls for a response. Physical disabilities are no longer considered an impediment to ordination. This has been true since 1983. Even earlier, some exceptions were made, but there is no need for special treatment any longer; candidates are accepted based solely on their ability to minister to others.

R.B., Florida

Comfort and Ideas

Your magazine has brought endless comfort and numerous ideas for both my husband and myself. Our four-year-old son, Dustin, has a seizure disorder and developmental delays. We had another son who died at 14 months of age as a result of similar problems.

Your magazine and the articles written by other parents have helped us to realize that we are very blessed to have such special people in our lives. Our eight-year-old daughter has learned endless facts of life that can't be taught in school. Keep up the great work; you provide a wonderful service!

D.C. & C.D., Illinois

A Father Speaks Out on Inclusion

I have just finished reading my first *Exceptional Parent* magazine and have enclosed my subscription. I am very impressed with two things. First is the regular feature of *Fathers' Voices*. So many times, fathers are left alone to deal with their struggles and emotions, wondering how their child with disabilities will turn out. The second thing that impressed me were the stories about inclusion.

Our 11-year-old-daughter, who has Down syndrome, has just been "dumped" into a segregated training center, 20 miles from home. That means she will spend between two and three hours a day on a school bus. She

Remembering Jordie

EXCEPTIONAL PARENT has been a wonderful source of support for us. We always looked forward to receiving each issue and always found a comforting and/or motivating article in it.

In November 1993, our son, Jordan, died. Since his death, we have continued to receive your magazine, but have been unable to bring ourselves to read it. But when the June 1994 issue arrived, I opened it to the CHILDREN'S PAGE and read "Remembering Daniel," Nathan Reiff's moving story about the life and death of his brother. Nathan's story was one I could really relate to, and it made me want to share our story.

I have enclosed a letter that we sent to my family and friends after Jordan's death. I wondered if you might print it with Jordan's picture? Our little Jordan taught us to be "exceptional parents." This is something all of us must learn, but we are lucky enough to have exceptional teachers—our children with disabilities. Unfortunately, not all children with disabilities have the opportunity to grow up and show us what their true potential would have been, but whatever amount of time they are here has a profound influence on those people they touch.

Jordan Leslie was born on August 8, 1992. By the time 1993 rolled around we had accepted the fact that he had some sort of disability, and found ourselves in an unfamiliar world of surgeries, tests, therapies and constant challenges. We spent most of the year dealing with fabulous medical, support and therapeutic professionals. Their support, along with the support of friends and family, helped us learn to enjoy Jordan as a developing and happy little boy.

Jordan made great strides in 1993. His initial reaction to a new task was usually anger; Jordan had terrific lung capacity! But once he decided to try something, he would put all his effort into it and eventually become quite proficient.

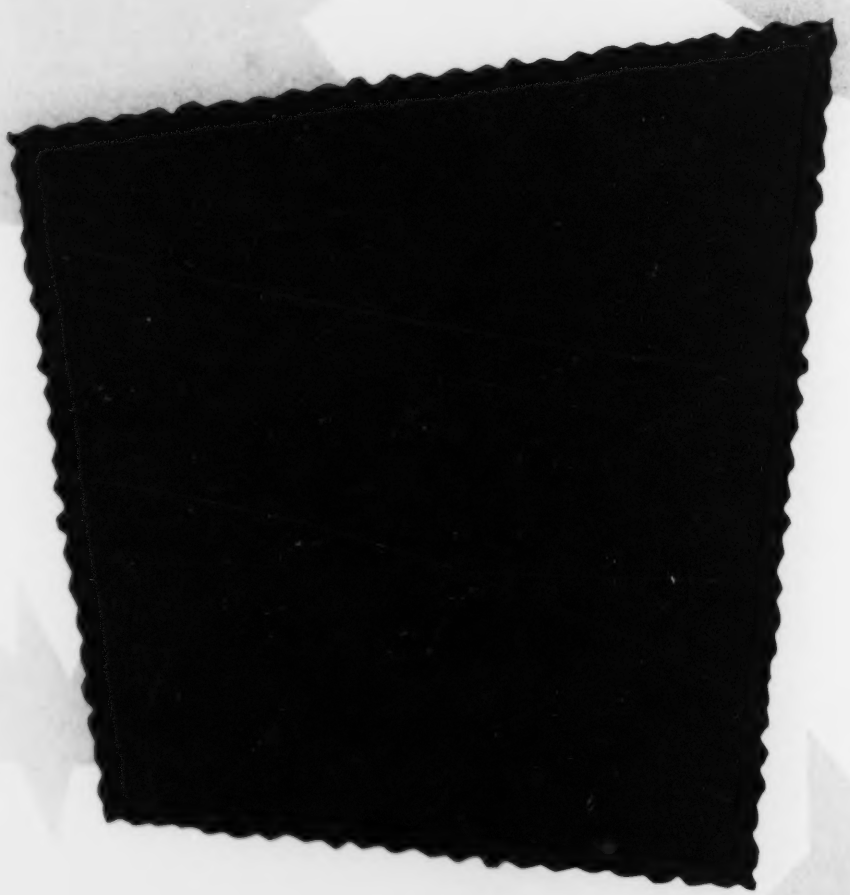
By September, Jordan had gained head control and enjoyed sitting up in his new wheelchair. Jordan's brother, Wade, would play hide and seek with Jordan by talking to him on one side of his chair and then running around behind the chair and surprising him on the other side. Jordan and his sister, Jessica, enjoyed playing peek-a-boo. Jordan had a very hearty laugh and found Wade and Jessica very amusing.

Just as we thought we had a handle on our new life, our little Jordan passed away. On November 2, 1993, Jordan went into the hospital to have some of his medications adjusted—we were used to this routine. On Thursday, the hospital unexpectedly called and told us Jordan had taken a turn for the worse. By the time we arrived at the hospital, he had already fought back from one episode with severe shock. He opened his big, beautiful, blue eyes and smiled at us—a moment we will always treasure. Early in the morning on November 5, Jordan went into shock again; this time he couldn't come back.

Jordan taught our whole family that everyone is worthy of as happy and fulfilling a life as possible. He also taught us about the power of determination. Although many of his accomplishments were small, they seemed larger than life to us and we celebrated each one. The little things in life are the most important, but they are also the things that most people take for granted. Our New Year's resolution is to take particular note of those little things that Jordan taught us to recognize and treasure. Thanks Jordie and God bless you—we all miss you so much.

—A.G. & R.G., Saskatchewan, Canada

708



in the Spirit of Giving

This holiday season, Kuschall of America is delighted to make a gift of twenty new wheelchairs to individuals chosen by an independent committee of judges.
To apply or for more information, in the USA call 1-800-654-4768
or in Canada call our distributor Motion 2000, (416) 494-2949.

kuschall of america

Circle # 47

had been attending a program at a school just around the corner. Now the school system is telling us that our daughter must be "protected" from a regular middle school environment.

I have written letters and made phone calls requesting a reevaluation of her placement. People tell me that I don't understand that the professionals know what is best for our daughter.

I will look forward to reading *Exceptional Parent* every month. Please help us get inclusion accepted everywhere.

R.Z., Florida

Wheelchair Tennis

We enjoyed Stephano Cargnel's article about the way sports changed his life ("Becoming a Contender," May 1994). After reading Stephano's story, I just had to send you a picture of my daughter's tennis group. Like Stephano, my daughter, Danielle (front right), and most of the other children in this photo have spina bifida.

We travel an hour each way from our home in S[illegible]n, Oregon so Danielle can be part of the Kids On The Move tennis program in Portland. It is a wonderful program that has added so much to Danielle's life and the lives of the other children. I can't say enough about how important these activities are. Thank you for publishing Stephano's wonderful article.

Tennis players (clockwise from top left) Bryan, Eli, Ryan, Danielle, Colin and Dan enjoy a Saturday afternoon on the courts at Western Athletic Club in Portland, Oregon. Kids On The Move tennis, basketball and archery programs are sponsored by the Northwestern Wheelchair Athletic Organization.

D. M., Oregon

Prejudice or Oversensitivity?

I was extremely surprised by the letter written by J.L. of California (August 1994) which said that the language in a previous letter revealed prejudices. The writer of that previous letter, the parent of a child with Down syndrome, had stated that she was thankful her child did not have physical disabilities.

J.L., the parent of a child with a physical disability, took great offense to that statement, but I think she missed the point—many of us thank the Lord every day that our children are no worse off than they are! This does not amount to prejudice against children who have different disabilities than our own. Speaking for myself, I thank God that my child seems to be right on target intellectually despite having very severe physical disabilities. If my child had different disabilities, I would still be very thankful for anything he could do. Just because we try to look at the bright side of our individual situations does not mean we think less of children or families who are dealing with a different set of circumstances.

"If we want the world to value our children—to stop segregating, stigmatizing and staring at them," as J.L. put it, we need to be proud of our kids for what they can do, and we need to allow other parents to be proud of and thankful for their kids, too.

No, J.L., I don't think the letter you responded to was insensitive. Please allow us to be happy for the blessings we receive without feeling that it is an insult to you or your son.

K.T., Tennessee

EXCEPTIONAL PARENT

- ***To reach out to parents** of children with disabilities and special health care needs.*
- ***To empower mothers and fathers** by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

LISA BLUMBERG, J.D., Corporate Attorney, Aetna, Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Waltham, MA
SANDRA B. FLEISHMAN, Parent, Project Director, A WORLD OF DIFFERENCE Institute, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, Pomona, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President Emeritus, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

710

Disability Really Isn't That Romantic

Thank you for publishing Elaine Greenbaum's opinion piece entitled "Disability Really Isn't That Romantic" (July 1994). As the mother of a child with multiple disabilities, I found it affirming and refreshing to read about the realities—not just the miracles or major achievements—of life with a child who has disabilities. We all need to keep a positive attitude and to push for better things for our children, but as much as we love happy endings to our family stories, we can't always make them happen.

Greenbaum's piece exposes our short-sightedness. We work so hard to prepare our special children for the "world," only to find that economic realities mean there are far fewer options out there than we were led to believe. If we put as much medical, social and parental energy into helping young adults with disabilities "make it" in the world as we put into newborns at risk, we would be in good shape. We need to look at our priorities.

K.H., North Carolina

☐ I read Elaine Greenbaum's article with some sadness. I have worked in state government for more than 20 years and have had the opportunity to see how various laws which were passed to resolve specific issues can have unexpected or unintended results—one person's solution can become another's problem.

As the parent of a child with significant disabilities, I have worked hard—with varying degrees of success—to have him involved in the mainstream of life. I quickly realized that his disabilities were not the reason he was excluded. His greatest barrier to inclusion is the ignorance and prejudice of others who grew up and were educated in a world that did not include people with disabilities. The regular education teachers who found it difficult to adapt curriculum materials for Greenbaum's son are prime examples.

Greenbaum worries that the existing forms of financial support to people with disabilities serves as a financial disincentive to work. But I think discrimination is a bigger problem. We should worry more about ending discrimination so people can strive for jobs in keeping with their abilities. Only then can we begin to worry about financial disincentives.

The Americans with Disability Act (ADA) gave us a new box of tools, *not* a magic wand. I have had several recent conversations about the ADA with people who do not have disabilities but who now work with people who do. Their ignorance about the law was discouraging. These people did not think people with disabilities had the right to participate in programs open to the general public or use public facilities.

If we do not use our rights, we will lose them again. We need to begin a campaign of public education to ensure a high level of awareness and understanding of the ADA. We need to have discussions with the people who teach our children so they understand and respect our children's rights and act in a manner which increases our children's sense of their own inherent worth.

M.R., New York

The issue number listed in September 1994 was incorrect. September was Vol. 24, Issue 9. EXCEPTIONAL PARENT apologizes for the error.

SPECIAL PRODUCTS FOR SPECIAL PEOPLE

New Expanded Catalog
More Therapeutic And Recreational Products To Help Everyone Enjoy Success

Gross Motor • Aquatics • Active Play • Manipulatives
Positioning Aids • Adapted Toys/Games/Furniture
Plus SNOEZELEN...sensory stimulation products, introducing KIOSK, an all-in-one new portable package.

Quality Products! Fully Guaranteed!

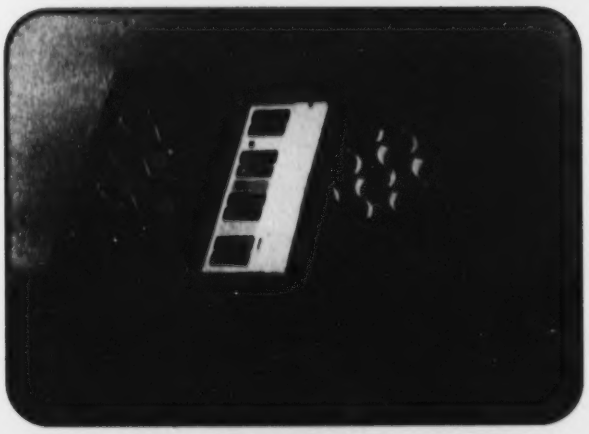
FLAGHOUSE INC.
150 No. MacQuesten Pkwy., Dept. 96024 Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

FREE CATALOG OFFER

Circle # 29

WOOD-WORKS

TOYS



Adaptive wood toys that are educational, fun and age appropriate.

For Information contact: Danmar Products,Inc.
(800) 783-1998

Circle # 243

SEARCH

Voice Amplification Equipment

My five-year-old son has a muscle disease known as centronuclear myopathy. His language skills and speech are excellent. However, his voice is so soft that it is difficult, if not impossible, to hear him in a classroom or group situation.

Can anyone recommend voice amplification equipment that he might be able to use? It would have to be compact and portable so he could use it in and out of his wheelchair.

D.C., Ontario, Canada

Partial Deletion of Chromosome 8

We are the proud parents of a three-year-old boy who has been diagnosed with partial deletion of the short arm of chromosome 8. My husband and I love our son dearly and hope to find someone who has a child with similar problems.

Anthony has been diagnosed as having mild to moderate mental retardation. He was born with several heart conditions—atrial septal defect and pulmonary and aortic stenosis. He also has hypospadias (a condition in which the urethral canal opens on the underside of the penis, before reaching the tip) and undescended testicles. His facial features appear normal.

We have been unable to find much information about this disorder. We would like to be in touch with other families who have had experience with this disability so we can know what his future may be like.

J.B., Illinois

Down Syndrome and Nonverbal

My seven-year-old daughter has Down syndrome. Jennifer started speaking at age two and a half, but by three and a half, she had stopped. During this time period, she had frequent ear infections resulting in two sets of ear tubes and an adenoidectomy. Recently, she had her tonsils removed. Before Jennifer stopped speaking, she was able to say approximately 75 understandable words.

In addition to the speech services she receives in school, Jennifer has attended private speech therapy sessions two times a week for more than three years. I can't say I have seen any benefit from these services. Jennifer vocalizes but says nothing understandable. While I know it is common for people with Down syndrome to have intelligibility problems, her problem is more severe.

We have taught her to use sign language and have provided her with an augmentative communication device. She understands what is said to her and will try to vocalize, sign and use the augmentative communication device to communicate. Her signs are immature and inaccurate due to her low muscle tone. She is beginning to use the augmentative communication device, but still uses it mostly to respond to someone rather than to initiate a conversation or request.

Jennifer has always been in an integrated educational setting and is included in first grade this year. As she gets older, it is getting harder for her to communicate with her peers.

I would like to talk with other parents of children with Down syndrome who are nonverbal, especially parents of children who stopped talking for no apparent reason. I haven't given up the hope that Jennifer will speak again, but at the same time, I am trying to face the reality that she probably won't ever speak intelligibly. I would really appreciate any advice and support as well as tips on communicating with a child who is non-verbal.

K.E., Illinois

Augmentative Communication Aids

Our child has a physical disability that affects only his gross motor skills; his fine motor abilities are good. He has just started school and we are investigating augmentative communication aids. I would like to hear from parents who have had good and bad experiences with augmentative devices for their children.

D.F., Texas

EDITOR'S NOTE: See "Augmentative and Alternative Communication Devices" (June 1994). This article lists a number of factors that parents should consider when choosing an appropriate augmentative and alternative communication (AAC) device for an individual child. A list of manufacturers of AAC devices follows the article.

Disability Awareness in Public Schools

My 10-year-old son, Allan, has Asperger syndrome (a type of "high-functioning" autism) along with some neuromuscular dysfunction. He is extremely

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

Tell us about...

...your successful and unsuccessful experiences with child care for a preschooler with a disability.

(You don't have to be the current parent of an infant or toddler to participate. If you have ever dealt with this issue, we would love to hear from you!)

Write to: Child Care, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax).

bright—possibly even gifted in the areas of science and social studies. Allan's school has finally agreed to allow him to be mainstreamed for these subjects.

Although more inclusion for Allan has been one of our goals, we are concerned because the school has done nothing to educate the other children about disabilities. I have seen children be cruel to Allan in the past, however, when I explained about his disability, the teasing gave way to acceptance. We feel that awareness and education will promote acceptance of our son and other children with disabilities who are now included.

The special education liaison at my son's school agrees that something needs to be done. We want to establish an educational program for regular-education students that will promote awareness and foster acceptance of people with disabilities. I would like to hear about good curriculums, model programs, books, puppet shows or any other disability-awareness tools have been used in public schools. Allan's school has agreed to review anything I can present.

M.G., Florida

EDITOR'S NOTE: See page 33 for an article about FRIENDS WHO CARE, a disability-awareness curriculum from the National Easter Seal Society. EXCEPTIONAL PARENT is eager to hear about and report on other, similar programs.

Klinefelter Syndrome, 48-XXXY

I am looking for parents of children with Klinefelter syndrome or 48-XXXY. My 14-year-old son has this condition. He has a lot of problems, but his doctors don't know if they are all related to his chromosomal abnormality.

P.T., Pennsylvania

EDITOR'S NOTE: Information on Klinefelter syndrome is available from: Klinefelter Syndrome and Associates, P.O. Box 119, Roseville, CA 95661, and Klinefelter Syndrome Association of America, P.O. Box 93, Pine River, WI 54965.

The National Institute of Child Health and Human Development (P.O. Box 29111, Washington, DC 20040, 301/496-5133) also offers a free booklet with up-to-date and very complete information on this condition. Ask for UNDERSTANDING KLINEFELTER SYNDROME: A GUIDE FOR XXY MALES AND THEIR FAMILIES.

Identical Twins Who Are Different

We are the parents of 10-month-old identical twin boys. I had a complication of pregnancy called twin-to-twin transfusion. To explain it simply, blood intended for one twin (the donor) was diverted to the other (the recipient).

The twins were born seven weeks prematurely. One of the twins (the donor) has been diagnosed with spastic quadriplegic cerebral palsy and a cortical vision impairment. He also developed infantile spasms at six months. These fortunately responded to one month of ACTH. The other twin is developing normally. We also have a three-year-old daughter.

We would love to hear from other parents of twins—especially identical twins. We would like suggestions for coping

continued on page 71

kid-kart™
cares about kids.

kid-EZ.
tilt/recline™

made in USA
PATENT PENDING

Proving good looks, convenience and proper positioning work wonderfully together.

kid-EZ. Adjustable High Chair Base

* Three Models
* Grows from infant to age 7
* Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle # 46

RESPOND

Vomiting Problem

J.K. & T.K. (June 1994) are the parents of one-year-old Jimmy, who was born with meconium aspiration and a grade-IV brain hemorrhage. Jimmy, who has cerebral palsy, a seizure disorder, cortical blindness, temperature instability, diabetes insipidus and a poor suck/gag reflex, is fed exclusively though a G-button. Jimmy had a G-tube, but it was replaced with a G-button when he was three months old, which was when he began vomiting. Since then, the amount of formula he can take in without vomiting has decreased from six to two ounces per feed.

Gastrointestinal scans show some reflux, but anti-reflux and stomach medicines have not helped. Jimmy has had trouble gaining weight, despite being fed every few hours with a high-calorie, concentrated formula.

Our 17-month-old son, Zachary, was also born with meconium aspiration and an unknown amount of brain injury caused by the lack of oxygen to his brain. Like Jimmy, Zachary has cerebral palsy and experienced seizures for a few days following his birth. He also has temperature instability and a poor suck/swallow reflex. Zachary is fed primarily through a G-tube, although he is capable of eating orally if we remain quite persistent.

To enable us to meet his total caloric needs, Zachary had a NG-tube inserted at three months of age. At nine months, this was replaced by the G-tube; at the same time, the Nissen procedure was done to prevent reflux. We began giving Zachary his feeds by venting his tube to allow for any air or vomiting episodes to occur out of his tube.

At about 12 months of age, Zachary began to exclusively vomit orally. His vomiting episodes had no particular pattern and did not seem related to the volume of his feedings.

Zachary began to vomit large quantities—sometimes as often as five to eight times a day. Zachary has had the pH probe test twice and has also had the upper-barium test. Both tests indicated only a small amount of reflux and some occasionally fluctuating pH levels.

Like you, we have tried various medications—including Zantac, Reglan, Cisipride and Bethanecol—with no success. However, Zachary takes regular doses of Donital to calm his stomach waves, and it seems to be moderately successful. Zachary also suffered from inconsolable irritability—the Donital has helped substantially in improving his mood without causing him to become lethargic.

We also use a high-calorie formula and have used a number of additives, from MCT oil to simple baby cereal. Although you did not say, we hope you have a feeding pump, as it does help in the slow continuous flow of the feeds.

Zachary also has a lot of "pooling" of mucous in the back of his throat because of his poor swallowing reflex. We find that he vomits less frequently if we are able to keep this mucous under control. Elevating his upper torso during feeds seems to help.

Zachary's vomiting has decreased somewhat with age. We give him a slow continuous feed during the night to supplement what he needs for growth. Although we fight for every ounce, we have gradually been able to increase his weight.

K.C. & C.C., Georgia

EDITOR'S NOTE: J.K. & T.K. received a number of responses to their SEARCH letter. We invited Dr. David Hirsch (ASK THE DOCTOR) to comment on these responses. Dr. Hirsch noted that almost all of the parents who responded described similar evaluations and trials of medications and formulas with their own children. Some of these medications may work on an individual child, often in conjunction with a formula change, a change in feeding method (e.g., drip versus bolus or open versus closed systems) or the addition of food additives (e.g., polycose, MCT oil or concentrated formula powers).

Dr. Hirsch noted that some children seemed to "outgrow" the problem. In others, a relatively easy solution (such as a change in positioning) or the use of a commonly available medication (such as Donital) made a useful difference. In another case, the diagnosis of a rare condition and its appropriate treatment "cured" the vomiting problem. While all cases are different, Dr. Hirsch added that most have significant similarities that may lead to relatively straightforward solutions.

Two Children With Spina Bifida?

D.H. & D.H. (August 1994) are the parents of a two-year-old daughter with spina bifida and a three-and-a-half-year-old son, who does not have a disability. They are thinking about having another child, but doctors have told them they would have a small chance of having another child with spina bifida. D.H. & D.H. wanted some insight on what life would be like with two children with spina bifida.

We read your letter and felt like you were talking to us! We have three children—Michael, 8, Colin, 6, and Bethany, 4. Colin and Bethany both have spina bifida.

We did not know Colin had spina bifida before he was born. Things happened very fast; in fact, his whole newborn period is a big blur in our memories. We grieved, read everything we could get our hands on and eventually came to terms with the situation. We tried to carry on and to make our lives as "normal" as possible. We even learned to feel fortunate because Colin's lesion was fairly low (L5–S1), and his prognosis for walking was good.

When Colin was about a year old, we began to discuss whether and when to have another child. We decided fairly easily that we wanted another baby because doctors told us we had a two to three percent chance of having another child with spina bifida. To us, that meant a 97 to 98 percent chance of having a healthy baby—so much for statistics!

Just as we had decided to wait a year to have another child—so that Colin would be walking better—we discovered the question was moot! The new baby would be born around Colin's second birthday. We immediately began shopping for a double stroller.

A level-II ultrasound at about 15 weeks gestation revealed that the new baby did, indeed, have spina bifida. Of

714

Bed-wetting won't bother him tonight. And you can't see why.

Pull-Ups® GoodNites™ absorbent underpants are the first ones ever made for bigger children–45 pounds and up.

They're superabsorbent, yet so thin, they all but disappear under pajamas.

The child slips them on and–accident or not–wakes in a clean, dry bed. With a whole new positive attitude.

GoodNites™ will help keep kids dry until they outgrow bed-wetting. Since 3 million kids share this problem, that's a lot of good mornings.

Get the GoodNites™ Guide for Kids–yours for sending just $1 postage and handling to: GoodNites™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

® Registered trademark of Kimberly-Clark Corporation. © 1994 KCC

"GoodNites™ mean Good Mornings."

Circle # 163

A MOST ACCESSIBLE STORE

The Apple Computer Disability Solutions Store
Call: 1-800-600-7808; 1-800-755-0601(TTY).

course, we cried. Although we knew the risks and had been confident that we could handle having another child with spina bifida, we had hoped this baby would be okay. We took the ultrasound pictures to our neurosurgeon for a consultation. We learned that the baby's lesion was in the *LA* area, and that everything else seemed fine. With this information, and with what we already knew about spina bifida, we felt comfortable about our decision to continue the pregnancy.

We continued to monitor the baby's development with frequent ultrasounds and made plans for a C-section. Things went well and we were thrilled to have a daughter.

Now, Bethany is four. It is hard to believe these years have passed so quickly! In a way, the first few years are hard to remember because we were so busy. It was hard to keep up with double diapers, two sets of braces and double therapy sessions. And going anywhere required a fair amount of planning and equipment. But we figured it all out and did whatever we would have done anyway. At first, we felt very conspicuous going places with our two strollers and two little pairs of crutches, but we soon got used to it.

We have found that having two children with spina bifida is not all that different from having one child with spina bifida. We both feel that it was easier the second time around because we were better prepared. We have even discussed the idea that having a sibling with a similar disability might actually be beneficial to a child, in that they feel less "different." Having two children with spina bifida also helps us avoid putting too much pressure on one child.

Of course, having two children with spina bifida is no picnic! There are times when the little inconveniences can really add up, but we try to keep our sense of humor and to rely on friends for moral support. We also are aware of Michael's needs—with so much time and energy devoted to the other two children, we try to make sure Michael receives his share of attention.

For us, the decision to have a third child was the right one. Bethany has such a strong, engaging personality that it is hard to imagine our family without her.

J.D. & E.D., Pennsylvania

Simplified electronic messaging

Provides full Internet capabilities

Easy to search special education databases

Customized services and pricing packages

Interactive user interface

Accessibility to special education bulletin boards

Link to special educators, associations, parents, & students

National, "800", customer support number provided

Electronic fax delivery options

Training materials included

GTE

GTE Educational Network Services
1-800-927-3000, ext. 8507
Internet Address INFO@gteens.com

Circle # 265

716

Obsessive Compulsive Disorder

P.P. (July 1994) has a 10-year-old son who has been diagnosed with obsessive compulsive disorder (OCD) and is currently taking medication. He also has some learning disabilities. P.P. wanted to "compare notes" with parents of similar children.

Our 11-year-old daughter was diagnosed with OCD a year and a half ago. Like your son, Laura has some learning difficulties; she also has a progressive hearing loss. We have found OCD to be another challenge in her life, but a manageable one.

Laura's OCD is manifested in compulsive hand washing. The symptoms became quite pronounced before we realized what was going on. Laura was quite distressed by her compulsions, so it didn't take us long to seek professional help. Fortunately, we were quickly referred to a child psychiatrist who has had experience working with children with OCD. He reassured us that it is a biochemical disorder, and is quite treatable. Laura has been on medication since her diagnosis and is doing very well.

Laura continues to have some difficult behavior, but as we have learned about OCD, some of it has become easier to understand and manage. Laura has always been somewhat anxious and fearful, and does not adapt easily to change. We have learned to give her clear, concrete directions and plenty of warning when her routine needs to change. She responds well to structure and becomes anxious when she has "time on her hands." She enjoyed going to day camp several weeks this summer.

Laura has always behaved well at school, but she needs structure in that situation, too. When she was younger, it helped her to have a written schedule for each day.

We have discussed OCD with Laura's teachers. None of them had previous experience with this disorder, so we felt it was important for them to understand the anxiety that is part of the condition. They have all been very supportive, and have been able to give Laura reassurance when she needs it. If Laura's teachers had not been willing

continued on page 76

AWESOME!

...just *begins* to describe kids' reactions to riding the *STEP 'N GO*™ Cycle.

There's never been a cycle like it!

Here are three great reasons why a *STEP 'N GO*™ is ideal for your child *-and no other cycle has them!*

- **Our Patented Tredl Transmission™** automatically responds to your child's natural range of motion. They pedal up and down instead of 'round and 'round!
- **Our Easy Balance™ Design** provides maximum stability by placing your child within the "Triangle of Safety."
- **One Size Fits All!** There's no need for complicated sizing and measuring before you purchase. Kids of all sizes from 60 pounds and up can easily ride and enjoy *STEP 'N GO.*™ Plus the rugged design and affordable adaptations mean they'll never outgrow the fun of a *STEP 'N GO*™ Cycle!

They'll feel safe and in control.

30 Day At Home Trial

Call Us Today for Complete Information by 1st Class Mail

1-800-648-7335

(802) 425-2264 Ext. 254

Patented © 1994 TPI

You Gotta Try It!

STEP 'N GO™ Cycles

Treadle Power, Inc., P.O. Box 180, Cedar Beach Rd., Charlotte, VT 05445

Circle # 266

Now he has a place for everything like everyone else.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

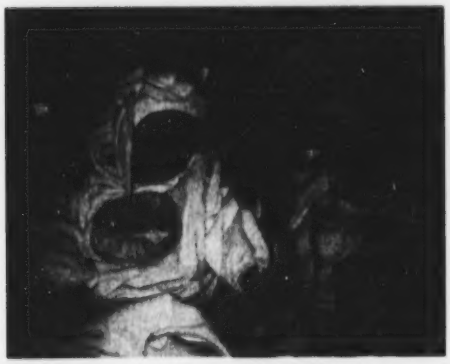
1-800-4-MYDESC

RHAMDEC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2240
MYDESC is a trademark of Rhamdec, Inc.

Circle # 103

FAMILIAR FACES



*"Mooo-ve over, sis," says **Kyle Blecha** (right). Big sister **Rachel Blecha** was the cutest little bunny in Kewaskum, Wisconsin last Halloween. Rachel, now 3, has cerebral palsy. She loves to play outside on her swing and with her new puppy, Rose.*

*He didn't scare too many crows last Halloween, but three-year-old **Michael Andrew Verdin** of Tulsa, Oklahoma did a great job of trick-or-treating. Michael has tuberous sclerosis.*

***Lee Joseph Grube** is a very happy little boy who loves to show off for friends and family. Dressed as a pumpkin last Halloween, he got his fair share of attention. Lee, who will be two years old in January, has multiple disabilities. He lives with his parents Lee and Angela in Champlain, Minnesota.*

*It was no wonder **Matthew Charland**, 5, of Manassas, Virginia, made a jolly jester last Halloween. Matthew, who has Kabuki Makeup syndrome, is always entertaining everyone with his sense of humor and funny antics, says his mom, Amy.*

*He may have been "Oscar the Grouch" for Halloween, but **Jeffrey John Lewis**, 5, was a happy grouch when he won two prizes for his costume. Jeffrey, of Esapus, New York, had a left hemispherectomy in July 1993 to remove Rasmussen syndrome, a rare brain disease. Although he was left with some paralysis on his right side, it doesn't stop him from doing much.*

718

*Grandpa **Gino Fioravanti** enjoyed spending last Halloween with this little tiger from Penfield, New York. **Nicholas Fioravanti,** 3, loves to dress-up for Halloween, says mom Julie. Nicholas has cerebral palsy.*

***Linda Fahnestock** (right) and her granddaughter, **Jordynn Rae Lakatos,** made a great pair of Raggedy Anne twins with the costumes Linda made for Jordynn's school Halloween party two years ago. Jordynn, now 6, lives in Torrance, California. She is undiagnosed, but has microcephaly, a seizure disorder and other disabilities.*

*Who says trolls can't be cute? Donna Jensen says daughter **Annan Leigh Jensen** "is the cutest troll I know." Twenty-eight-month-old Annan was born with tracheomalacia and now has cerebral palsy. Annan lives in Gulf Breeze, Florida.*

***Kristin Costanzo,** 7, loves to clown around at Halloween. Kristin, of Altamonte Springs, Florida, attends a private Catholic school and enjoys ballet lessons. She has Down syndrome.*

*With a mobile of flying bats and ghosts above her head, witch **Desirie Lord,** 8, clutches her broom and prepares for a night of tricks and treats. Her mom, Elizabeth, says she always tries to make Desi's wheelchair a part of her costume. Desi, who has cerebral palsy, lives in Centerville, Virginia.*

*Where's Tinkerbell? Brothers **Joseph Keawe Broc** and **John Kealoha Broc** won first prize for their Peter Pan and Captain Hook costumes at a contest sponsored by a shopping center near their home in Haleiwa, Hawaii. The boys' grandmother, Juanita, made the costumes—even sewing long ringlets of hair to the inside of John's Captain Hook hat. Joseph, now 6, has spina bifida.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent?* Send it to: Readers' Photos, *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

719

ASK THE DOCTOR

by David Hirsch, M.D.

Irritability

Q My 14-year-old daughter has cerebral palsy and hydrocephalus requiring a shunt. She is mentally retarded and nonverbal. She gets most of her feedings by gastrostomy button, but can eat some pureed foods which she really enjoys. The problem is that she has recurring episodes of irritability lasting from three to five days at a time. During these periods, she is irritable for three to four hours at various times each day and will not take any food by mouth. She may have five to ten good days in-between. We have taken her to the doctor for this, but she always seems to be fine in the doctor's office.

These recurring bouts of irritability make it difficult to plan family social events or for my husband and I to go out and leave her unless we have skilled respite care. Is there anything we can do to find out the cause of this irritability and help her through these times?

A Irritability, in a child with a disability, whatever the cause, is one of the most difficult and frustrating problems for both parents and health care providers—not to mention how frustrated the child may become. In individuals with multiple medical problems and the inability to communicate, the cause of the irritability can be very difficult to determine. Acute (sudden, short-term) irritability may have an obvious cause such as an ear infection, gastroenteritis (stomach flu) or trauma. With chronic (ongoing, long-term) irritability, the cause may not be complicated even though it is not immediately obvious. To further complicate the diagnostic process, an irritable child will often be fine when brought to the doctor's office. Nevertheless, chronic irritability is extremely stressful for the child and parents, and as you pointed out, can make it extremely difficult to schedule family functions.

Chronic irritability may have multiple causes, but major causes can be categorized as physical (most cases) and psychological:

• **Gastrointestinal reflux** (abnormal backflow of stomach contents) is probably one of the most common physical causes of irritability, especially for children with cerebral palsy who are tube fed. Symptoms of reflux may include vomiting or poor weight gain. Sometimes, however, irritability may be the *only* symptom.

Some forms of reflux are easily treated with changes of feeding methods, for example using the drip method (where the feeding is given slowly over a number of hours) as opposed to bolus (where the feeding is given over a much shorter time period at a much faster rate). Venting, opening the button or feeding tube to allow more air to escape from the stomach, may decrease reflux, too. A doctor may also prescribe medications or changes in positioning.

More severe forms of gastrointestinal reflux may require more complicated evaluations by your child's physician or a gastroenterologist, and more aggressive treatment.

• **Chronic constipation** is another very common problem in children with disabilities. If you have ever suffered from "irregularity," you know that it can be painful and can become a chronic problem if left untreated. Modifications of diet and the use of natural laxatives, fiber or other approaches recommended by your child's physician may take care of this problem. (See *Ask The Doctor*, July 1994.)

• More severe gastrointestinal disorders such as **gastritis, ulcers and other forms of digestive tract dysfunction** may also cause chronic, recurrent irritability. Diagnosis of these conditions may require extensive evaluation.

• **Orthopedic problems** such as dislocations, especially of the hip, and subtle fractures, often not associated with known trauma, may be aggravated when the child moves. This causes pain and irritability. X-rays or other imaging studies may be needed, especially after a thorough examination reveals a painful area.

***Ask the Doctor** is a regular department of EXCEPTIONAL PARENT in which questions from readers are answered by David Hirsch, M.D., a board-certified pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Whenever possible, Dr. Hirsch makes specific suggestions. However, since Dr. Hirsch is responding to letters and will not have personally examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch occasionally mentions specific products or medications, he is doing so to illustrate his suggestions; he is not endorsing any specific products.

*To submit a question to Dr. Hirsch, write or fax: **Ask the Doctor**, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

720

Change Someone's Life. Give Exceptional Parent magazine... the gift that keeps on giving!

12 issues for $18

Special Holiday Rate!

EP

12 issues for $18
SPECIAL HOLIDAY RATE!

Gift Cards Will Be Sent

Gift To:

Name (please print)

Address Apt.

City State Zip

Gift To:

Name (please print)

Address Apt.

City State Zip

From:

Name (please print)

Address Apt.

City State Zip

- Process my own subscription/renewal at $18 &
- Process my ___gift subscription(s) at $18
- My total order equals $ _____
- Payment enclosed (use separate envelope)
- Bill me

Offer expires December 31, 1994. Canadian Rate $24.00. Foreign Rate $27.00. 341

EP

12 issues for $18
SPECIAL HOLIDAY RATE!

Gift Cards Will Be Sent

Gift To:

Name (please print)

Address Apt.

City State Zip

Gift To:

Name (please print)

Address Apt.

City State Zip

From:

Name (please print)

Address Apt.

City State Zip

- Process my own subscription/renewal at $18 &
- Process my ___gift subscription(s) at $18
- My total order equals $ _____
- Payment enclosed (use separate envelope)
- Bill me

Offer expires December 31, 1994. Canadian Rate $24.00. Foreign Rate $27.00. 341

Change Someone's Life. Give Exceptional Parent magazine... the gift that keeps on giving!

12 issues for $18

Special Holiday Rate!

No Postage Necessary If Mailed In The United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

No Postage Necessary If Mailed In The United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

• **Certain neurological problems** may also be difficult to detect in children who cannot communicate. Migraine-like headaches may cause pain and irritability which is periodic but not usually daily. In children with other neurological problems such as cerebral palsy, some of the other symptoms seen in classic migraine, such as sensory and motor disturbances (certain visual disturbances, temporary paralysis or numbness of an extremity among others), may not be recognized.

• **Central nervous system shunts** are special plastic tubes that drain excess fluid from the ventricles of the brain. A child with a shunt that is working only intermittently may experience episodic pain and irritability without the more pronounced symptoms of a sudden shunt failure. If there is any question about the functioning of your daughter's shunt, her pediatrician or neurosurgeon should be contacted.

• **The effects of medications and combinations of medications** that are used on a continual basis may cause irritability by themselves or may lead to other problems, such as gastritis, that cause irritability.

• If your daughter has started menstruating, especially if she has had periods for a year or two, she may be experiencing periodic bouts of **cramping**. This is another potential source of episodic irritability.

• A **feeding anxiety or aversion** is a possible psychological cause for irritability. If your daughter has had previous experiences with feedings that made her physically uncomfortable, she may have developed worries or fears about the act of eating. In this case, she would probably be more likely to seem irritable around feeding times. If possible, it may help to eliminate those factors that seem to make the child uncomfortable with feeding. If necessary, trying a different feeding method may work.

• **Psychological problems** are harder to diagnose in children who have severe medical problems. Many health care providers feel that a child with a medical condition such as cerebral palsy cannot also have psychological problems such as depression, anxiety and/or compulsive behavior. This mistaken belief is especially common if the child in question is mentally retarded. But my experience suggests that psychological problems, especially those described above, are at least as common in children with disabilities.

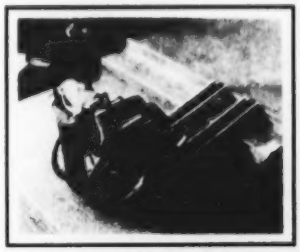
Your child's pediatrician should be able to refer you to a neuropsychologist or a developmental psychologist or psychiatrist who has had experience treating children and adolescents with developmental disabilities.

These are the more common causes of irritability that I see daily in my practice. There are many others. Please consult your daughter's physician for further evaluation.

EZ-ACCESS™

The Leading Name in Portable Wheelchair Ramps

Look for this Seal of Quality

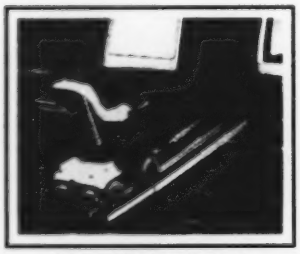


Rollup/3' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

- Anodized Aluminum
- Non-skid Surface
- Telescopic Design
- Catch Buttons
- One Year Warranty

R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'

R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle # 40

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Funding Power Wheelchairs

Q I have a five-year-old son with cerebral palsy. He is not able to walk on his own, but he has the ability to get around with a children's power wheelchair.

My insurance company will only cover the costs for a manual wheelchair. Is it possible to get coverage for a power wheelchair if it is recommended by a therapist? Also, is it likely the insurance company would cover the cost of buying a used power wheelchair?

A When people purchase a health insurance policy, they often assume that the insurance company will provide reimbursement for the cost of all medical services and equipment, aside from the usual deductibles and co-payments. That's a reasonable assumption, but it's not always the way the system works.

Many insurance policies specifically exclude coverage for certain services or equipment, including power wheelchairs—sometimes listed as "durable medical equipment." The first question, then, is whether your insurance policy has such an exclusion. That information should be clearly listed in your policy manual (if it's a group policy, check the "master contract").

If no exclusion of power wheelchairs is listed, you need only to demonstrate that the equipment is "medically necessary." That requires "documentation"—letters from your child's doctor and physical or occupational therapist describing your child's condition and explaining why he cannot use a manual wheelchair.

It is important to ask the doctor and therapists also to list any additional wheelchair-related equipment your child may need, including special seat belts, switches, remote-control devices or other items. If additional equipment is listed in the original claim, and is medically necessary, the insurance company may pay for it. But if it is not part of the original claim, many insurance companies will pay only for the wheelchair.

Some insurance companies require that power wheelchairs meet certain specifications before they will pay for them. One way to ensure that your choice meets those specifications is to file a request for the insurance company to make a "pre-determination of benefits" before you purchase the chair. (Check with your insurance company to determine the procedure and forms the company requires.) The process generally takes three to four weeks. The insurance company usually will respond with a written statement approving or rejecting the claim.

Power wheelchairs and related equipment can be expensive. And since children's needs may change rapidly, it is not unusual for a child to need a new power chair every three or four years. If such items are not covered by your health insurance policy, you may wish to try to find a policy that does cover them. Large group insurance policies—generally offered as an employee benefit in a large company—frequently have the fewest exclusions.

Alternative Funding

If it is not possible to switch to an insurance policy that provides coverage for power wheelchairs and related equipment, another alternative is to try to obtain funding from local charitable or civic groups, or from state agencies. Although the main function of state vocational rehabilitation agencies, for example, is to help people with disabilities make the transition to full employment, these agencies or others may occasionally provide funds for medical equipment for children as well.

In addition, some state health departments include a program designed to help meet the medical needs of children with disabilities. That program may be able to provide funds for the purchase of a power wheelchair for a child. Under certain circumstances, the local public school district may also be able to help, as long as the need for the power wheelchair is included in the child's Individualized Educational Plan (IEP).

Used Wheelchairs

Insurance companies usually don't deal with used equipment. In fact, they generally won't even accept the return of a used power wheelchair when the company is replacing it with a new one. Insurance companies could, I think, perform an important public service by donating used power wheelchairs and other expensive equipment to social service agencies and needy families.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To insure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.

724

At Last, a Financial Plan and Someone Who Knows How To Help You Use It:

Your Financial Consultant.

Merrill Lynch has over 80 Financial Consultants who are specially trained to meet the needs of the deaf and hard-of-hearing community. Through the use of TTYs and voice amplification, they can provide you with access to all of Merrill Lynch's services and research. They will begin by discussing your current situation, your financial concerns, and your objectives with you. This information can be used with our fee-based Financial Foundation® Service to provide you with a personalized financial plan that you can readily understand and act upon to reach your financial dreams.

The plan recommends concrete ways you can:

- Reduce income taxes
- Allocate and build investments
- Protect your family from loss of income
- Meet education expenses
- Finance your retirement
- Plan your estate

Take the first step in planning your financial future by calling your Merrill Lynch Financial Consultant and asking about the Financial Foundation Service.

The difference is Merrill Lynch.

Call 800-637-7455*, ext. 8239

*If you are deaf, you can call 800-765-4833, ext.8239
If you are hard-of-hearing, you can call 800-765-4HOH, ext.0000

For more information about our Financial Foundation® Service, send to:
Merrill Lynch Response Center
P.O. Box 30200, New Brunswick, NJ 08989-0200

Name _____ Address _____

Business Phone _____ City _____

Home Phone _____ State _____ Zip _____

Merrill Lynch clients, please give the name and office address of your Financial Consultant: _____

8239

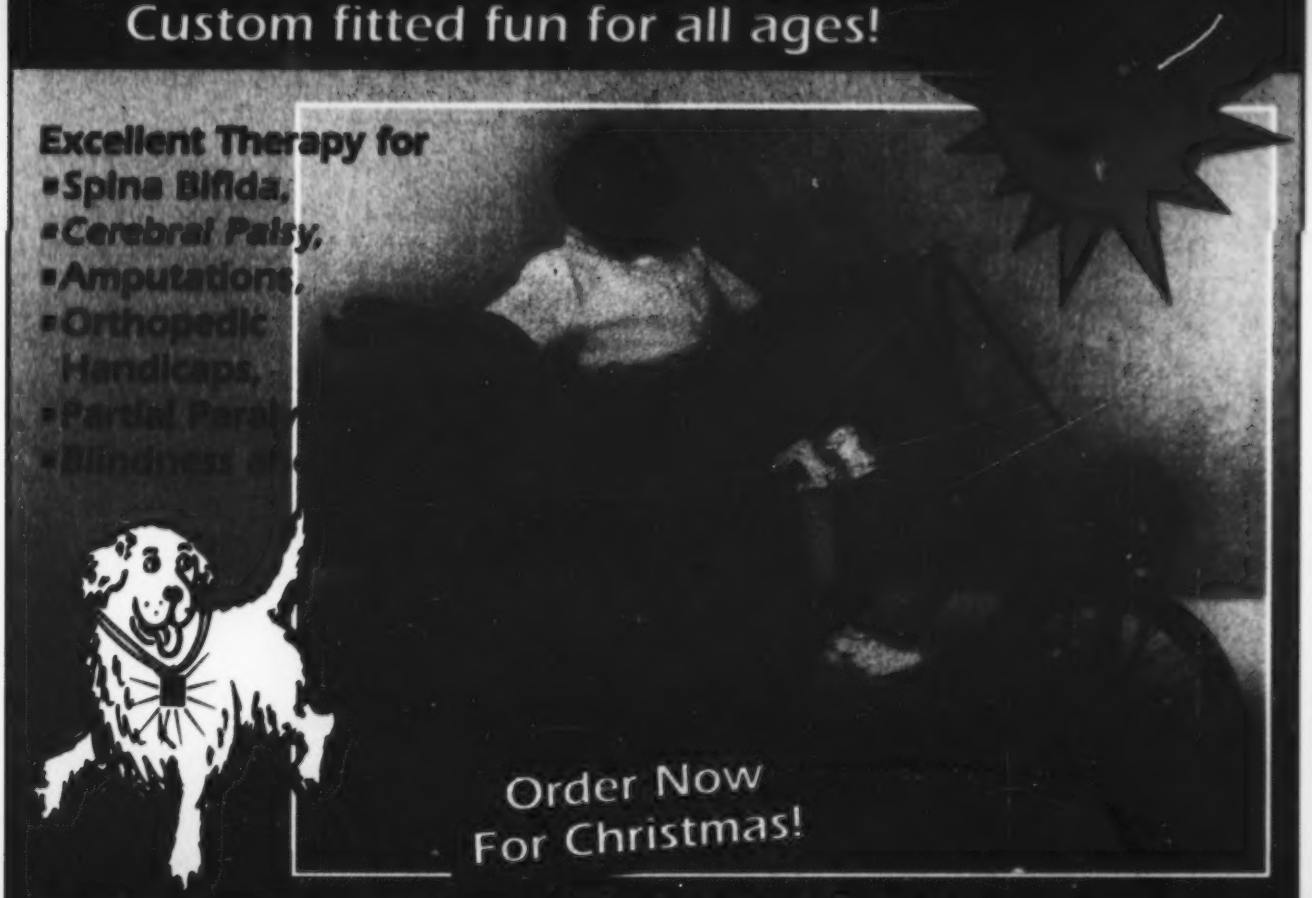
Merrill Lynch
A tradition of trust.

©1994 Merrill Lynch, Pierce, Fenner & Smith Inc. Member SIPC.

Circle # 168

Rock N' Roll CYCLES

Custom fitted fun for all ages!



Excellent Therapy for

- Spina Bifida,
- Cerebral Palsy,
- Amputations,
- Orthopedic Handicaps,
- Partial Paral
- Blindness or

Order Now
For Christmas!

Therapy ▪ Exercise ▪ Fun

Harilyn Rousso

Sex, Lives and Disability

Harilyn Rousso is the founding director of the Networking Project for Disabled Women and Girls in New York City. She is the author of DISABLED, FEMALE, AND PROUD! *and executive producer of the documentary video,* POSITIVE IMAGES: PORTRAITS OF WOMEN WITH DISABILITIES. *She is a member of the board of directors of the Ms. Foundation for Women, the editorial advisory board of* EXCEPTIONAL PARENT *and a former commissioner with the New York City Commission on Human Rights.*

Rousso began painting about six years ago because of a "real desire to do something that was a little less intellectual and a little more visually oriented." She says she wants to include more people with disabilities in her paintings "because I don't think we see ourselves out there in the art world."

When Rousso was growing up, doctors advised her parents to keep her away from other kids with disabilities. "My parents," Rousso says now, "were a product of their generation; they believed if you had a disability you couldn't have a social life."

I was, in my mother's mind, very eager to be born because I wanted to arrive before the doctor even got to the hospital. My mother didn't know I had a disability until I was about one and a half when I seemed to be somewhat delayed, particularly in walking. Doctors told her she was being a hypochondriac on my behalf. When I was finally diagnosed with cerebral palsy, she didn't know too much about it. The doctor told her that although I had cerebral palsy, I was very smart and should be kept away from other kids with disabilities and raised like a "normal" child. I think this attitude was a reflection of a time when people didn't expect or realize people with disabilities were normal.

I attended public schools in New York City. If the principals had any hesitations about my enrollment, my guess is that my mother talked them out of these doubts fairly quickly. Throughout my school years, I never knew other students with disabilities. If there were others, I never saw them. At that time, special education classes were even more segregated—they were much more like separate schools.

I only had friends without disabilities. I played all of the games, including punchball. I may not have played as well as kids without disabilities, but I did well enough to be part of the group. Of course, there were also the kids who made fun of, pointed at and ostracized me. They—particularly the older boys—would ask what my problem was and they would imitate me.

The teasing was very painful, but I also felt like, "This is who I am, this is my body, this is how it looks, this is how it acts. I want to be me. I don't want to have to live up to people's expectations." Sometimes I would look in the mirror and be surprised at what I saw. In a way, I felt like everyone else, but I was confronted with some images that said I was different, and it was startling. I think I began to feel even more isolated in my teenage years when the focus shifted from just playing games to the social scene.

A Social and Sexual Life?

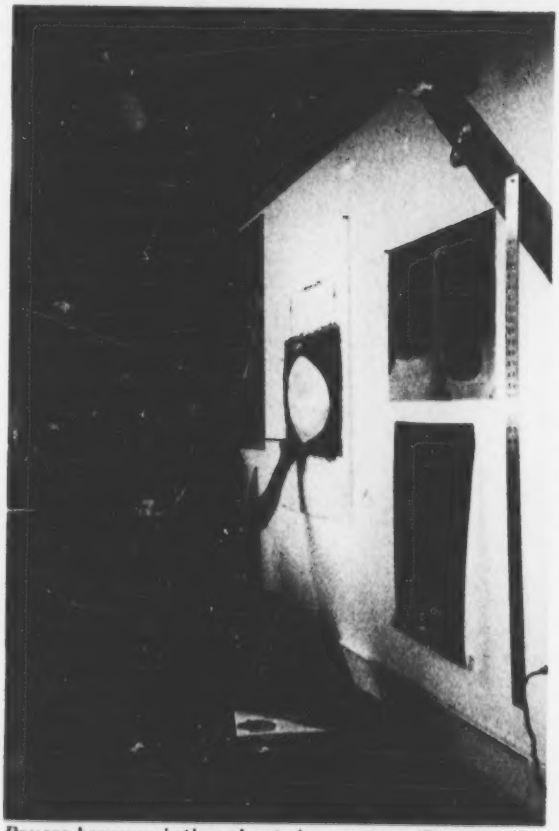
During my teenage years, my friends started dating, thinking about boys, getting periods and developing breasts. Although I went through all that, I felt that I was not going to be part of the dating scene and that sex, marriage and children were not possible for me. My sister, who is five years older than me, taught me some things and I learned others by observing other kids or by reading pamphlets

about menstruation in Kotex boxes. However, I didn't think the information had much relevance to me. I concentrated instead on my studies. I thought my role was to do very well in school and to get good grades and just to achieve. It wasn't until I was in my 20s that I began to consider the possibility of a social and sexual life.

Overcoming Stereotypes

When I was 22, I had an unexpected, but important experience. I worked one summer for a prominent woman economist who had cerebral palsy. When I interviewed for the position, it was like looking in a mirror. Her effects on me are still with me. I was impressed that a woman with cerebral palsy could become so successful in her career, particularly in the "man's field" of anti-trust economics. Married to a wonderful man, Betty gave me the ability to see that I could have both a career *and* a social life.

My self-esteem really began to improve when I found a career I liked, being a psychotherapist. However, my road to a career was not an easy one. When I completed a Master's degree in social work, I went on for advanced training in psychotherapy. After attending a psychotherapy training institute for a year, I was asked to leave because some of the teachers did not think that a person with my disability should become a psychotherapist. They claimed that my disability would be too stressful for patients to handle. They suggested I consider a different career. It was shocking to me—the super achiever who had always done so well was told she couldn't succeed. Consequently, my life as a disability rights activist began after I successfully sued the institute.



Rousso began painting about six years ago "because of a real desire to do something that was a little less intellectual and a little more visually oriented." She wants to include more people with disabilities in her paintings.

The Women's Movement

At some point I achieved a certain level of self-confidence to be able to consider not just my brains, but my whole self. I wanted more than just to be smart. I became involved in the women's movement. Although I was the only woman with a disability involved with my women's groups, I had a real sense of commonality with the other women. I realized that a lot of reasons that I felt different—my body wasn't right, I didn't look a certain way or I wasn't graceful—were the same for women without disabilities. I felt much more a part of the sisterhood of women than ever before.

Networking Project for Disabled Women and Girls

In 1984, I approached the YWCA of New York City to sponsor a mentoring program I wanted to start for girls with disabilities. Named the Networking Project for Disabled Women and Girls, the project allows women and girls with disabilities to meet and share experiences. I wanted to help girls with disabilities avoid certain things that I had experienced, especially the isolation and the acceptance of negative stereotypes. Participants in the project talk openly about various topics, from jobs to relationships and sex. Here, women and girls can see others who are doing interesting things in their lives, who have parties, children, jobs and lives. I want girls to feel OK about themselves at age 13 rather than waiting until age 30.

Disabled, Female, and Proud!

A few years after I started the Networking Project, I wrote a book to help young women with disabilities learn about the experiences of women who had "been there." Published by Exceptional Parent Press in 1988, *Disabled, Female, and Proud!* profiles 10 women with disabilities.

I'm now working on a project to bring attention to the problem of sexual harassment of girls with disabilities. As women with disabilities, we face a double set of prejudices based on gender *and* disability. Girls with disabilities are often easy targets of sexual harassment because they are seen as quite vulnerable. I'm trying to document the problem, publicize it and hope to design programs for girls to feel more empowered, to train them to avoid harassment and encourage them to report instances of alleged harassment.

I'm also working with Girls Incorporated, a national youth organization. I'm working with them on modifying

Rousso has been involved with her partner, Gene Brown, for eight years. "I have a wonderful relationship," she says. "For him, my disability is part of the many parts of who I am."

their Operation SMART program that addresses the under-representation of girls and women in science and math so that it is accessible to girls and young women with disabilities. More jobs require a knowledge of scientific principles, but because girls with disabilities are stereotyped as helpless, dependent and not smart, they are denied exposure to math and science. The program's goal is to develop a curriculum for girls with and without disabilities to learn math and science together and to obtain the needed skills, attitudes and opportunities to pursue science and math courses and careers.

Looking back

I guess it would have helped me to have had relationships with adults and peers with disabilities who I could have looked up to. My parents were a product of their generation; they believed if you had a disability you couldn't have a social life.

Hopefully, things have changed. Parents should be more hopeful that their daughters can have relationships and be socially active, and should express that hope to their children with open and honest discussions. I would love girls to have a real sense of pride in their femaleness, pride in being precisely who they are—disabilities and all. I deeply feel that every woman really has wonderful potential and that she needs to have friends and family and an environment that helps her to celebrate herself.

DISABLED, FEMALE, AND PROUD! is available through the EXCEPTIONAL PARENT LIBRARY for $12.95 plus postage and handling. To order, call (800) 535-1910.

For more information on POSITIVE IMAGES: PORTRAITS OF WOMEN WITH DISABILITIES (not available in home-videocassette format), contact Women Make Movies, Inc. at 462 Broadway, Ste. 500, New York, NY 10013 or call (212) 925-0606.

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

Together We Will Reach Our Journey's End —

A Better World for Children with Disabilities

For more than 75 years Civitans have enjoyed working together to help people in their communities.

Civitans worldwide share your hope for a bright today, and a brighter tomorrow. It is that hope which built the Civitan International Research Center for developmental disabilities, and it is that hope which lights our path.

Join us. Together we will reach our journey's end.

Building a Better World Since 1917

☐ I'm interested in community involvement. Please send more information about Civitan service clubs in my community.

☐ I want to support the research underway at the Civitan International Research Center for developmental disabilities. Please send more information.

Name _____

Address _____

City/State/Zip _____

Telephone Number ( ) _____

CIVITAN INTERNATIONAL, P.O. BOX 130220, BIRMINGHAM, AL 35213. (800) CIVITAN

Circle # 186

729

Grieving a Dream

by Susan Blanchard

In March 1992, my first and only child was born. I had a delightful pregnancy; despite some nausea at the beginning, I was very happy being pregnant. I loved feeling my child inside me. I envisioned a labor ending with my child being laid upon my chest, everyone smiling and happy.

I didn't get the dream I envisioned. Marie was born not breathing. Doctors immediately carried her to a table on the other side of the room to be revived, then rushed her out of the room to the neonatal intensive care nursery. Alone in the delivery room shortly after her birth, her father and I wondered if she would live. We cried, but mostly we were in shock. Nothing could have prepared us for a birth like this.

Later, when I learned that my daughter had cerebral palsy, I didn't just cry; I wailed. I went home and I cried and I wailed and I was very loud about it. I did not like this news; I did not want my daughter to have a disability.

Taking the Blame

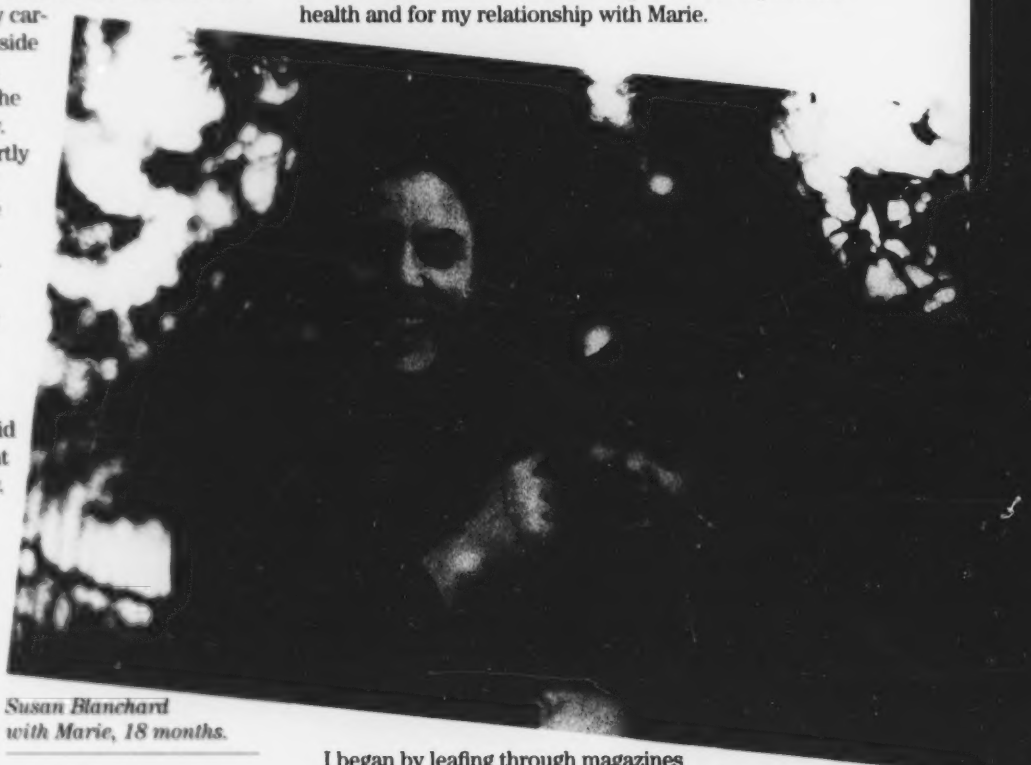
I believed God was punishing me for past sins—if only I had done something differently, my daughter would not have cerebral palsy. If only I had picked a different doctor; if only my body had not been in labor so long; if only I had finished that art piece before her birth. It was easier to take the blame for Marie's condition than to accept it.

I desperately wanted to talk with other parents who had been through similar experiences. I finally found a group sponsored by the Arc of Multnomah County—a seven-week support group entitled "Accepting a Difference." The parents in the group discussed how hard it had been to find emotional support for our experiences. How wonderful it would have been if someone had been there to offer support immediately following a traumatic birth, someone to counsel us during and after the initial diagnosis.

Finding other parents who understood my pain helped me to stop blaming myself for Marie's condition. I began to see the child beyond the disability. Even though I didn't get the daughter I had dreamed of—one who could walk and talk and move independently, I had a daughter who was beautiful, sweet and happy. Still, the "dream child" I had wanted hovered in my consciousness, sometimes blocking the view of my real-life daughter.

Grief Ritual

Other members of the group suggested that I do a "grief ritual." As soon as I heard these words, I knew I would do this ritual, and that it would be important for my mental health and for my relationship with Marie.



Susan Blanchard with Marie, 18 months.

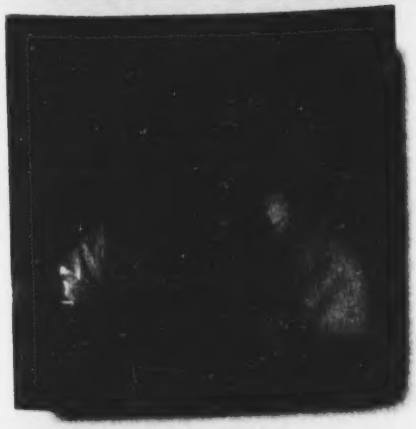
I began by leafing through magazines to find pictures of my "dream child"—the child I didn't get. I cut out any picture that moved me. I especially looked for pictures of the ideal birth where everyone is smiling and the wet, shining baby is laid on the mother's chest. I found pictures of babies sitting up and crawling, of young girls running and playing.

I cut out a paper doll from a large piece of blank paper and was amazed that holding this piece of paper to my chest caused me to cry. I glued my dream child pictures all over the paper doll. I decorated her with glitter, paint and colorful markers. I cut out a back for her, and stuffed her with more of my "dreams." I wrote the ideas that corresponded to each of my dreams directly onto the pictures I had cut out. It was important to make this paper doll as real as possible, to name each of my dreams and to bring them into the light so they could no longer haunt my subconscious.

continued on page 28

730

"CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.



AND THEN BACK OUT AGAIN."

At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

After all, we were the first automotive company to establish an assistance program for the physically challenged—years before most of the others. And since then, Chrysler's Physically Challenged Assistance Program (P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

And now the program offers you more than ever before. Higher cash reimbursements—up to $1,500 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. Complimentary three-year Cross Country Motor Club membership. A friendly, knowledgeable P-CAP Resource Center to help answer all your questions. And complete Chrysler Credit financing to qualified buyers.

All topped by more experience assisting the physically challenged than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. We'd like to make it easy for you and your family to get into—and out of—a new Chrysler Corporation vehicle.

P-CAP

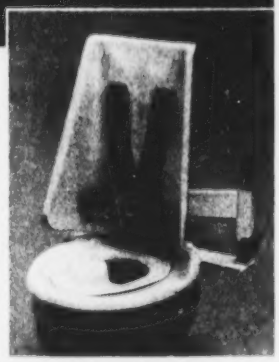
CHRYSLER CORPORATION

For more information on the Physically Challenged Assistance Program, call us at **1-800-255-9877**.

Circle #90

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support



The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 11

Paul Blanchard with Marie, 15 months.

After my paper doll was stuffed and decorated, I held her in my arms and cried some more. This was my dream child; I wanted to hold her, but I knew I needed to let her go. I love the daughter I have; I didn't want my grief about her disability to get in the way.

Four friends gathered to help me with the ritual. Each of them shared stories of lost children and lost dreams. I then presented my dream child to my friends and shared my dreams with them. I talked about all the things I had wanted but didn't get. I had decided to burn this dream child—to transform her energy and let her float away. So, after discussing my dreams with my friends, I put the paper doll in the fireplace, lit a match and let her go.

I had decided to burn this dream child—to transform her energy and let her float away. So, after discussing my dreams with my friends, I put the paper doll in the fireplace, lit a match and let her go.

After the fire died down, I shared the dreams that became reality for me—a wonderful pregnancy, being able to breast-feed, a loving and playful child. This process helped me to realize that although my child has a disability, many of my dreams about motherhood did come true.

continued on page 30

A River Runs Through It.

Introducing the River Tank Ecosystem.

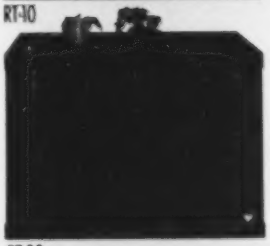
Your fish have been dreaming of this. A playground of sorts where they move up and down the rapids and waterfalls. And where they travel from pool to pool as they do in a natural river habitat.

Maybe you've been dreaming of this. A tank you never have to empty. A tank that let's you use real plants above and below the water. A tank that's entertaining and educational. A tank that requires little maintenance.

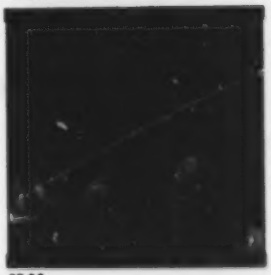
It's not an aquarium. It's not a terrarium.

The patented River Tank Ecosystem is a dynamic, living habitat where plants, fish, frogs and reptiles interact in ecological balance.

RT-10



RT-20



RT-30

Like a real river, the rushing water generates a healthy, oxygen-rich environment. When the water seeps through the gravel-filled plant cavity, biological balance is naturally maintained. And since plants use fish waste as food, there is no need for fertilizer.

There's a River Tank for every environment.

Homes. Schools. Workplaces. Now everyone can have a river view. The River Tank is available in four sizes: RT-10, RT-20, RT-30 and RT-45. It's very affordable. And you don't need a life preserver to enjoy it.

Call 1-800-808-8822 for more information or the dealer nearest you.

RIVER TANK SYSTEMS

PO Box 445, Exeter, RI 02822

© 1993 Fish Stream Designs, Inc. U.S. Patent No. 5,083,570

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

Finding Freedom

In the short time that has passed since I performed this ritual, I have felt a great sense of relief. I realize, however, that the grief process is a continuous one, and I will continue to seek support from other parents, my friends and my family.

I encourage other parents who have a child with a disability to be aware of the need to let go of their "dream child." A personal ritual or a simple prayer may allow you to express your grief in a safe way. Learning how to accept what is—and to let go of what had been hoped for—can be very liberating.

Our culture is not very practiced in expressing sorrow. Sometimes we feel guilty when we express disappointment or sadness. But if we don't express our grief, it will covertly affect us and those around us—most of all, it will affect the child with a disability.

I encourage other parents to get the help and support you need to deal with the sadness and disappointment that can come from having a child with a disability. Letting go of your dream child will give you and your real-life child the freedom to find your own way to a happy life.

Susan Blanchard is a legal secretary who lives in Portland, Oregon. She is an artist, avid nature walker and believer in magic.

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

Circle # 26

Absolutely No Rinsing Required

Just Apply | Massage | Towel Dry | Comb & Style

Less than 5 minutes for a cleansing shampoo

No-Rinse® Body Bath
Less than 10 minutes for a refreshing bath

No longer is bathing an ordeal

Truly Out of This World! No-Rinse Shampoo and No-Rinse Body Bath are used by NASA's astronauts on all of their space flights, and are available on all future missions.

N.R. Laboratories
No-Rinse®
The original liquid, non-rinsing hair and body cleansers

For Information and Samples:
900 E. Franklin St.,
Centerville, Ohio 45459
Toll Free 1-800-223-9348
FAX 1-513-433-0779

Made in U.S.A

Circle # 1

734

THE ONLY PRESCRIPTION FORMULATION OF LEVOCARNITINE IS NOW AVAILABLE FOR REIMBURSEMENT

- CARNITOR® (levocarnitine) is now available for reimbursement by Medicaid in all 50 states and Medicare in many states.
- CARNITOR® is the only prescription formulation of levocarnitine available and "...should not be confused with dietary and health supplement L-carnitine products.... Such supplements have not undergone review by FDA for safety and effectiveness."[1]
- "Unless these dietary supplements...have been approved...recommendations/ requirements by State Medicaid agencies would be inappropriate for the treatment of systemic carnitine deficiency."[2]
- **"The data from this and previous studies indicate a lack of quality control in the manufacturing process of tablets and capsules in products sold as food supplements, resulting in gross inconsistencies in the properties of the tablets to disintegrate under physiological conditions within a reasonable time. Furthermore, there is evidence that many of the products contain significantly less than the stated amount of the active substance, suggesting also a lack of quality control in the formulation of the product."[3]**
- **"Only the prescription form of levocarnitine is indicated for the treatment of carnitine deficiency. Over-the-counter and health food store products should never be substituted."[4]**

CARNITOR®
(LEVOCARNITINE)

**The Only Prescription Formulation!
Available in Tablets, Oral Solution,
and Ampoules for Intravenous Use...
And *Now Available for Reimbursement!***

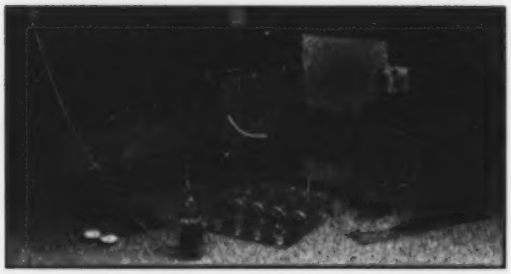
Please see full prescribing information on adjacent page.

Circle # 269

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

CARNITOR®
(LEVOCARNITINE)

The Only Prescription Formulation! Available in Tablets, Oral Solution, and Ampoules for Intravenous Use...
And Now Available for Reimbursement!



References: 1. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written communication from the Food and Drug Administration. 2. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written Communication from the Department of Health and Human Services. 3. American Medical Association. Therapy for inborn errors of metabolism. *Drug Evaluations*. Spring 1992: 8:I-8:5. 4. Millington DS, Dubay G. Dietary supplement L-carnitine: analysis of different brands to determine bioavailability and content. *Clin Research & Reg Affairs*. 1993;10(2):71-80.

CARNITOR® (LEVOCARNITINE) Tablets and Oral Solution
For oral use only. Not for parenteral use.

CARNITOR® (Levocarnitine) Tablets (330 mg)
CARNITOR® (Levocarnitine) Oral Solution
(1 g per 10 mL multidose)

CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency.
Tablets and Oral Solution are also indicated for the acute and chronic treatment of patients with an inborn error of metabolism which results in a secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS

General CARNITOR® Oral Solution is for oral/internal use only. **Not for parenteral use.** Gastrointestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3-4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests have been performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* that do not indicate that CARNITOR® is mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or whether to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion

Reference: Rebouce CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D, L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D, L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® Tablets: Recommended adult dosage is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution.
Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED CARNITOR® Tablets are supplied as 330 mg, individually foil-wrapped tablets in boxes of 90. Store at room temperature (25°C/77°F). CARNITOR® Oral Solution is supplied in 118 ml (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection
For Intravenous Use Only

CARNITOR® (Levocarnitine) Injection 1 g per 5 mL
CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS
Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion
Reference: Rebouche CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology.

OVERDOSAGE There have been no reports of toxicity from levocarnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea.

DOSAGE AND ADMINISTRATION
CARNITOR® Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter), and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

HOW SUPPLIED CARNITOR® (Levocarnitine) Injection, 1 gram per 5 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton.

Store ampoules at room temperature (25°C/77°F) in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

© 1994, SIGMA-TAU Pharmaceuticals, Inc.

Friends Who Care

Teaching children about disabilities

by Sara Brewster

As a first-year special education teacher in the late '60s, Sandy Gordon was appalled at the way her students were treated. "My kids were basically ostracized," she remembers. "Not only did other kids make fun of them, but so did the teachers and the principal. I saw what it did to their self-esteem. It was horrifying." Gordon vowed that someday she would do something to change things.

In 1987, as a senior vice president for corporate communications at the National Easter Seal Society, Gordon saw her opportunity to make a difference. Campbell-Mithun-Esty (CME) Advertising, Minneapolis had offered to provide creative services at no charge for Easter Seals' multi-media public service advertising campaigns. In the first months of this collaboration, Gordon and CME designed Easter Seals' *Friends Who Care* television and radio public service spots, print ads and posters.

Originally targeted to middle school students, the multi-media campaign generated hundreds of requests from elementary schools for materials to use in disability-awareness workshops. A grant from Ronald McDonald Children's Charities allowed Gordon and her staff to begin developing a hands-on teaching curriculum for elementary students.

In 18 months of research, writing and classroom testing, priorities for the *Friends Who Care* curriculum became apparent. First, the program had to use humor and an "in-your-face" approach to challenge negative attitudes about disabilities. Second, it had to provide essential information about the types of disabilities students were likely to encounter, and about the range of abilities within each disability. Third, enhancing the curriculum and helping people get beyond stereotypes and sympathy required guest speakers with disabilities; curriculum planners created guidelines for students and teachers to invite people with disabilities to talk about how they do things. This proved especially effective in allowing kids to see Brailled magazines, try out TTYs (which enable people who are deaf to use the telephone), learn words in sign language or see and touch racing wheelchairs.

In the fall of 1990, the *Friends Who Care* disability-awareness program was introduced to 20,000 schools nationwide. Kits included a 16-page teacher's guide—written in a style that would inform teachers without insulting them; a pre- and post-program attitudes survey; worksheets to expand the activities for sections on vision, hearing, learning, developmental and physical disabilities; guidelines for guest speakers; five posters; bookmarks with tips for disability etiquette and a 45-minute videotape to accompany specific activities.

Teachers have been enthusiastic. More importantly, students have written to Gordon about their enthusiasm for the program. "Your program has made me look at disabled

Mandi Rutherford (center) is surrounded by her third-grade classmates at the elementary school she attends in a town just north of San Diego, California. As part of a one-day FRIENDS WHO CARE program at her school in November 1992, Mandi took on the role of "guest speaker" to tell her classmates about her life with spina bifida. As part of her presentation, Mandi showed the class how she uses her wheelchair and crutches. She also talked about her adapted bicycle and roller skates.

Her participation in the program helped Mandi to feel more a part of her class. And Mandi's classmates now have a better sense of what it is like to live with a physical disability. Photo: Marshall Harrington.

737

HOLIDAY SPECIAL!

This holiday season, we want your child to benefit from Laureate's award-winning talking software. From now until December 30, 1994, we'll take 25% off any software program you order. We'll even pick up the shipping charges!

25% OFF all Laureate software

This offer applies to individuals only. No school, agency, or institutional purchase orders, please. Orders must be pre-paid by check, MasterCard or VISA. Sorry, but this offer does not apply to hardware and cannot be combined with any other Laureate special.

Call 1-800-562-6801 for a free catalog!

Over 60 talking programs for Apple II, Apple IIGS, IBM, and Macintosh computers.

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Circle # 48

people with a whole new perspective," wrote Justin Dwyer of Wisconsin.

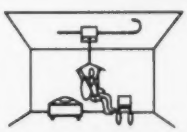
"I had a lot of fun. Now I know disabled people can do just about anything anyone can do," Krista Zywicki said.

Gordon wishes that we no longer needed to be teaching teachers and students about disabilities. "We're still a long way from fully accepting people with disabilities as people, and seeing them as individuals who have something to offer as students, friends, employees and volunteers in our communities."

But five years into the program, Gordon is optimistic and emphasizes that *Friends Who Care* is a starting point for the integration of students with disabilities into regular classrooms. "We can't begin to address the needs of students with disabilities in school without understanding what it means to have a disability."

Sarah Brewster, assistant vice president of corporate communications for the National Easter Seal Society, has been working with the FRIENDS WHO CARE program for five years.

A FRIENDS WHO CARE curriculum kit costs $25. Each kit includes a 16-page teachers manual, worksheets, letters explaining the program to parents, a 45-minute video, classroom posters and other materials that may be reproduced. To order, write or call: National Easter Seal Society, 230 W. Monroe St., Suite 1800, Chicago, IL 60606; (312) 726-6200, voice or (312) 726-4258, TTY.



Barrier Free Lifts

BARRIER FREE CEILING LIFTS ARE

- **Used independently!**
  Most physically challenged people can transfer themselves unassisted.
- **Air tube controlled!**
  No electricity to the user!
  No chance of being shocked!
  Can operate while in water!
- **Multi-directional!**
  Vertical & horizontal motion at the push of a button.
- **Battery operated & no maintenance!**
  Batteries are automatically recharged each time the lift is used.

Helping You Achieve Greater Mobility

Barrier Free Lifts, Inc.
P.O. Box 4163 • Manassas, VA 22110
(703) 361-6531 • FAX (703) 361-7861
1-800-582-8732

Circle # 217

RICON

Innovation in Mobility

Everyday Heroes

Protected By Our 5-Year PEACE-OF-MIND Limited Warranty

For more information about Ricon wheelchair lifts, call

1-800-322-2884

United States • Canada • United Kingdom • Norway

Ricon Corporation 12140 Montague Street Pacoima CA 91331

(818) 899-7580 Outside U.S. • (818) 890-3311 Fax

TOYS for Every Child

by Marilyn Hammond

Playing is one way that children experience and make sense of the world around them. Play helps children develop intellectual abilities, including language. They learn social skills through interacting with other children. And participating in physical activities improves strength and coordination.

Toys are an important part of play. Providing appropriate toys for children with disabilities may be challenging, but it can be done. Playing with toys can teach children about cause and effect. Most importantly, opportunities to control objects or events in the environment leads to feelings of success, self-confidence and mastery.

Isaac McMahon tries out a switch.

Commercially-Available Products

Often, widely-available commercial products are appropriate for many children with disabilities or require only simple adaptations. (For some examples, see pages 42–45.) Such products include magnetized shapes and letters, various kinds of building blocks, small musical keyboards or large ones that can be walked on, pop-and-go cars, large crayons of different shapes, books, sound-activated toys (see page 40) and marble chutes.

Minor changes may make it possible for children with disabilities to play with an existing toy. For example, changing the rules of a game may help a child with mental retardation, or a scooter board could supply the necessary mobility for some children to reach toys and explore their surroundings.

For a child with a motor impairment, restricting the movement of a toy—with a tray, box lid or pillows—may be the only necessary adaptation. Toys also will stay within reach if they are tied to a pegboard with string. Magnets, suction cups or Velcro may be another way to stabilize a toy. Rubber pads or light-weight carpet padding that is cut to fit the base of a toy is another good way to prevent skidding.

For some children, toys will be easier to grasp if handles are added or enlarged. Hanging or suspending toys within a child's reach may also help. A cubicle with several hanging toys can be constructed for a child who is blind. Children with visual impairments may enjoy tactile or Braille books, cards, dice and games, as well as gloves, frisbees and balls that beep. Many such toys are available through catalogs.

More Complex Adaptations Using Switches

Electronic games and battery-operated toys can be controlled by switches. Switches may also be used to control computers, environmental-control systems, appliances, cassette players and communication boards. Switches are available in many styles, shapes and sizes, and can be activated with various type of physical movement.

Many mail-order companies sell switches and adapted toys. Parents, teachers or therapists may also adapt toys for a specific child.

Inexpensive switches and battery adapters can be made at home with minimal training. For example, one easy and low-cost adaptation requires only the purchase of an inexpensive foot switch at Radio Shack or a similar store. The jack on this unit will fit directly into the remote jack of a standard cassette tape player. Unscrew the casing and replace the springs with foam so the switch will respond to a light touch. Many children enjoy being able to control a tape recorder to listen to music or talking books.

Several videotapes provide step-by-step instructions for making a variety of switches for various toys:

740

Becky Sisco enjoys geometric puzzles.

• *Toymaking.* Available from National Lekotek Center, 2100 Ridge Ave., Evanston, IL 60201, (800) 366-7529; $23.50, includes postage and handling.
• *Toys for All Children.* Utah Assistive Technology Program, Center for Persons with Disabilities, Utah State University, Logan, UT 84322-6855, (800) 333-8824; $27, includes postage and handling.
• *A Video Catalog.* Toys for Special Children, 385 Warburton Ave., Hastings, NY 10706, (914) 478-0960; $6.50, includes postage and handling.

Alliance for Technology Access (ATA) centers and/or state assistive technology programs may also be helpful resources for parents who want to learn to create switch-adapted toys. Call (415) 455-4575 for a referral to the nearest ATA center; to locate your state's assistive technology program, call RESNA at (703) 524-6686.

Toy Libraries

Probably the best way to try out different kinds of switches and toys is through a toy library affiliated with Lekotek or USA Toy Library Association. Toy libraries lend out toys, like a regular library lends books. See pages 46–50 for more information.

The Toy Guide for Differently-Abled Kids

The Toy Guide for Differently-Abled Kids is a 20-page booklet that aims to provide guidance to adults in selecting "off-the-shelf" toys for children with disabilities. A joint initiative of Toys "R" Us and the National Parent Network on Disabilities, the booklet provides full-color pictures and descriptions of more than 75 toys. Each toy is ability-coded for children with different disabilities. To receive a free copy, circle number 50 on the reader response card on page 67. (Please allow 3–4 weeks for delivery.) You may also pick up a copy at your local Toys "R" Us store.

Characteristics of Good Toys:

Whether toys are borrowed or purchased, some criteria for toy selection may include:
• *Fun:* Is the child enthusiastic about using the toy?
• *Age-appropriateness:* Do other children of the same age play with similar toys?
• *Ability level:* Does the toy match the child's current abilities?
• *Interactivity:* Does the toy move, make a sound or respond to the child's actions in some way?
• *Learning potential:* Will use of the toy contribute to the development of physical or intellectual abilities?
• *Socialization potential:* Does the toy promote interaction and communication with others?
• *Control:* Can the child operate the toy with minimal assistance?
• *Durability:* Is the toy sturdy enough to last with repeated use?
• *Safety:* Chose toys made from non-toxic, nonflammable materials without sharp edges or small parts that may be removed or swallowed. Watch out for strings or elastic that may entangle the child. Use only safety-inspected electric toys that plug into standard household electrical current.

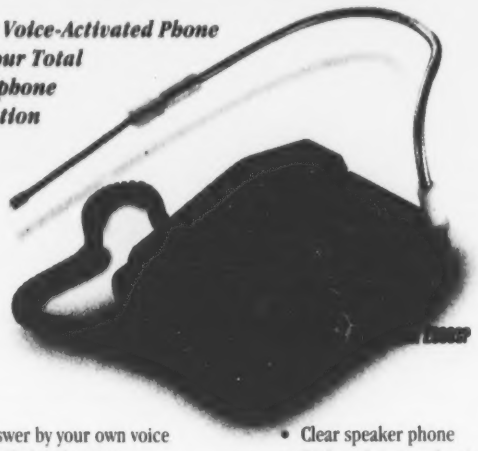
The condition of a child's toys should be monitored over time. Make sure batteries do not leak. Broken toys should be repaired or discarded. Frayed cords and wires can be replaced.

Providing play experiences for children with disabilities may involve hunting for appropriate commercially-available toys, making simple or more complex adaptations to existing toys or purchasing already-adapted toys. Through play, children can make choices, discover new ideas,

741

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution



- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

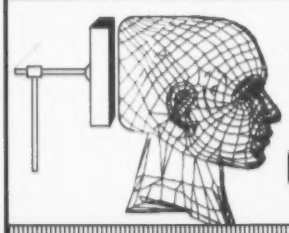
Order Now by Calling 1-800-847-8887

TEMASEK TELEPHONE INC.

Available in Black or Beige

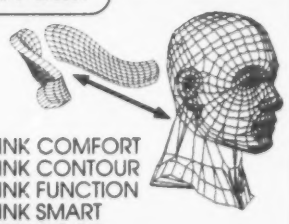
21 Airport Blvd. #G., So. San Francisco, CA 94080

Circle # 202



YOUR HEAD WAS NOT DESIGNED TO FIT INTO A FLAT HEADREST

GET YOUR CHILD "IN SHAPE" WITH A SOFT HEAD SUPPORT!



THINK COMFORT
THINK CONTOUR
THINK FUNCTION
THINK SMART
THINK S.O.F.T.

The Best Fitting System Available

WHITMYER BIOMECHANIX, INC.

Patented

848 Blountstown Hwy. Suite H (904) 575-5510
Tallahassee, Florida 32304 FAX (904) 576-4798

Circle # 188

The Battery Interrupter

This small device offers big benefits

By Steven E. Kanor

A little device called a battery interrupter allows parents of children with disabilities to easily adapt any battery-operated toy so it can be operated with a switch. The battery interrupter has a jack at one end and a disk at the other. To use it, slip the disk between the batteries of a toy and plug the jack into any of the special switches made for children with disabilities. Now, a child can operate the toy by activating the switch.

With the battery interrupter, there is no need to modify each toy separately or spend money buying already-adapted toys. You can use the battery interrupter and appropriate switches with any battery-operated toy. The battery interrupter can be removed when the toy wears out or breaks, and you can use the same battery interrupter in any other toy that takes the same size batteries.

The battery interrupter may be purchased from Toys for Special Children, 385 Warburton Ave., Hastings-on-Hudson, NY 107606, (914) 478-0960. The battery interrupter is available for AA, C and D batteries ($9 plus shipping and handling) and 9-volt batteries ($13 plus shipping and handling).

Dr. Steven E. Kanor is a rehabilitation engineer and founder and CEO of Toys for Special Children/Enabling Devices, a small company making 100,000 devices a year for people with physical disabilities.

Adapting a Toy With the Battery Interrupter

Everything you need: *(clockwise from left) A switch, a battery-operated toy, batteries and the battery interrupter.*

Position the battery interrupter.

With the battery interrupter in place, close the lid of the toy's battery compartment. The battery interrupter is now installed.

Once the battery interrupter's jack has been plugged into the switch, the toy can be controlled by the switch.

742

acquire self-confidence and acquire the skills that will allow them to develop to their fullest potential—and have fun!

Marilyn Hammond is a training and public awareness specialist for the Utah Assistive Technology Program for the Center for Persons with Disabilities at Utah State University. She has a Masters degree in Instructional Technology and is pursuing a Ph.D. in Family and Human Development. She has one child, a seven-year-old daughter, Michelle.

The author acknowledges the assistance of Mary Cadez and Amy Henningsen for their content suggestions, Nancy Noha for additional toy resources, Grace and Jim Sisco and Don and Penny McMahon for photographs and Martell Menlove for his support.

Guide to Toys for Children Who Are Blind Or Visually Impaired

The *Guide to Toys For Children Who Are Blind Or Visually Impaired* is a joint initiative of the Toy Manufacturers of America and the American Foundation for the Blind. The 20-page *Guide* provides full-color pictures, descriptions and age ranges for 70 commercially-available toys that are especially appropriate for children with visual impairments. To receive a free copy, circle number 194 on the reader response card on page 67. (Please allow 3–4 weeks for delivery.) You can also receive single or multiple free copies by sending a postcard to Toy Manufacturers of America, 200 Fifth Avenue, Suite 740, New York, NY 10010. The postcard should say that you want the *Guide* and should specify the number of copies requested.

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich ORTHOPÆDIC CYCLES

...rope's leading line of specialized
...cles, tricycles and tandems
...available in North America.
...frame. Duel caliper, drum
...coaster brakes available.
...ing brakes standard.
...styling and wide
...e of colour
...binations.
...than 30 specially
...igned accessories to
...every need.

Circle # 36

At Devereux...
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

743

TOYS

Forrest Pumps

A sound-activated water gun works without adaptations

by Jean Isaacs

When my son, Forrest, was about 15 months old, he got his first adapted toy—a police car complete with flashing lights and a siren. I remember holding out the big yellow switch as Forrest slowly moved his tiny fist to touch it. His eyes were so full of joy—finally, a toy he could control. Even with the big switch, Forrest had difficulty making the toy work; it was comparable to someone asking me to move a very large rock. Still, we all hoped that the fun of seeing the car move would motivate Forrest to gain more control of his arm movements.

A few weeks after the toy arrived, the therapist and I were working on Forrest's feeding skills while my other son, Fielding, was busy playing in our backyard sandbox. Involved in the therapy session, I didn't notice that the police car had been called upon to chase down a sandbox criminal. By the time I turned my attention back to Fielding, so much sand had been sucked into the motor that the toy no longer worked.

This incident prompted me to find a book about adapting toys. My first two attempts were disasters; following my "adaptions," the toys never worked again. The prices for switch-adapted toys in catalogs no longer seemed so unreasonable.

Finally, I took a class on adapting toys taught by Margaret Shuping, an instructor of computer technology in the Department of Special Education and Rehabilitation Counseling at the University of Kentucky. When I successfully adapted my first toy, I was empowered. Thus began an ongoing search for the next toy that would motivate my son to "move rocks." But the more toys I adapted, the less interested Forrest became in using switches to simply turn toys on and off.

Forrest Isaacs with his "Shout 'N' Shoot" water gun—"armed and dangerous!"

Learning to Play

I began to realize that there was much more to this play stuff than first meets the eye. Parents of typical kids simply buy them toys and they play with them. Forrest demanded a higher level of involvement, and I discovered that I didn't know how to play with him. I hit the books and started learning about the developmental levels of play. This knowledge gave me a whole new perspective on how to play with *both* of my children.

Soon, Forrest and I had come up with a few simple games. One of Forrest's favorite switch activites was playing "airplane." This game involved using a flashlight that had been installed in a shoe box with red cellophane and white construction paper to create a "fasten-your-seatbelts" sign. When Forrest used the switch to activate the light, the rest of us jumped around as though we were on an airplane experiencing severe turbulence.

We also hooked a switch to a red light inside a small, plastic cup. Once strapped over Forrest's nose with elastic, he was ready for his part as Rudolph in the Christmas play.

Another toy that kept Forrest's interest was a motorized water gun that we had adapted and placed on his wheelchair tray. This toy worked only as long as he could find "victims" to stand in front of his chair while he moved his hand onto the switch.

Around this time, Forrest's team of therapists and I decided to change the mounting of his switch from the wheelchair tray to under his chin. The chin switch gave Forrest a more efficient way to activate his electronic communication device.

744

Since Forrest no longer needed his hands to activate the switch, I mounted the water gun onto a Lazy Susan, hoping Forrest could use his limited arm movement to rotate the water gun and "aim." Due to his spasticity, however, the gun usually ended up aiming in a different direction than intended.

Water-Gun Party

Forrest's tenth birthday was coming up and after adapting every battery-operated car, truck and dancing bear I could find, I was fresh out of ideas. Then I saw a television commercial for "Shout 'N' Shoot," a hands-free, sound-activated, head-mounted water gun. Maybe this would work.

A week before Forrest's birthday, I located the water gun at the local Toys R Us. I asked the clerk if I could try it to see how much and what type of sound it required. We had tried other sound-activated toys in the past; they were either unexciting or required sounds that Forrest could not produce. I held the "Shout 'N' Shoot" and made an "eep" sound. Water came pumping out of the gun. I made a slightly softer, lower sound and out pumped more water; then a quick sound, and nothing happened. The sound-recognition switch seemed to require only a one-second sound slightly louder than clearing one's throat. Finally, I had found a toy that I didn't have to adapt!

At Forrest's birthday party, he blew out the candles on his cake with his battery-operated fan and switch. Then, he opened the present from Mom. I strapped the gun onto his head and adjusted the microphone. Forrest made a short sound and out came some water.

Forrest enjoys other types of water play in addition to his water gun.

He laughed, and out came lots of water. All his friends had been instucted that this would be a "water-gun party." To Forrest's amazement, all his guests pulled out water guns and the fun began in earnest. Forrest quickly found he didn't have to wait for someone to stand in front of him and wait for a soaking; all he had to do was shout and shoot!

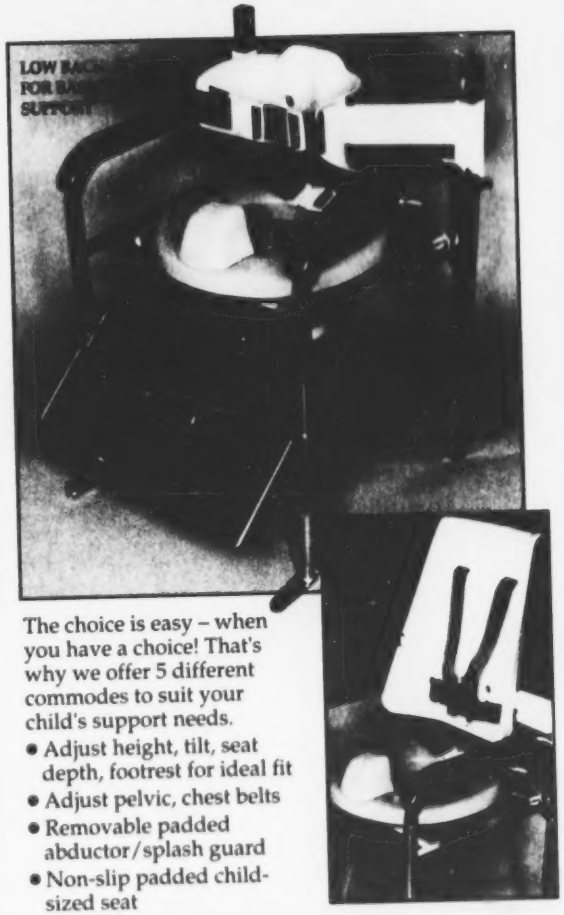
Jean Isaacs lives in Lexington, Kentucky with her sons Fielding, 11, and Forrest, 10. Jean works for an Alliance for Technology Access center, the Bluegrass Technology Center for People with Disabilities, which operates an adapted toy lending library.

"Shout 'N' Shoot," manufactured by Cap Toys, Cleveland, Ohio, is widely available at a suggested retail price of $15–20.

745

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet



The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 13

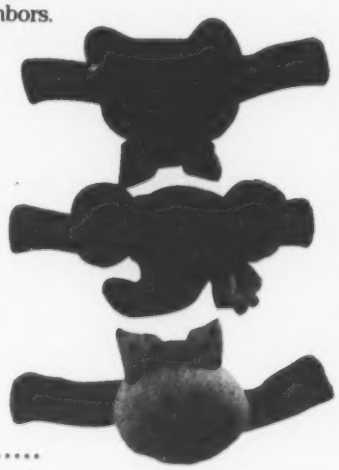
Using Ordinary Toys for Kids with Special Needs

by Joanne and Stephanie Oppenheim

This is the first of two articles adapted from the new 1995 edition of THE BEST TOYS, BOOKS & VIDEOS FOR KIDS (HarperCollins, $12) by Joanne and Stephanie Oppenheim. The book (available through EXCEPTIONAL PARENT LIBRARY, 800/535-1910) is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens. The 1995 edition includes an expanded chapter on adapting toys for children with special needs; it also includes books and videos of special interest.

All of these toys have been used with success by children with special needs. Many are especially easy to activate and provide interesting sensory feedback. Through play, children with visual or hearing impairments can learn to make effective use of their other senses. Similarly, children with motor impairments need products that respond to and motivate active exploration. While trying to meet the special needs of children with various disabilities, we also recognize that children enjoy playing with the same products as their siblings, cousins or neighbors. Adapting ordinary toys can put their play lives into the mainstream.

Most of the toys described below are readily available at, or can be ordered through local toy stores.



INFANTS & TODDLERS

Hot Tots BabyShakes *(Eden, $6.50)*
Soft-fabric rattles can be attached to baby's wrist or feet. All babies are fascinated to discover their limbs; these add-ons can help them refine more purposeful motions.

Listen & Learn Farm Animals Ball
(Texas Instruments, $24.95)
This popular 12-sided ball is activated by pushing the picture of an animal. Children are rewarded with the animal's sound and name in English. This toy can motivate kids to crawl and can develop hand-eye coordination along with naming skills. Note: this toy also comes in a bilingual (English & Spanish) version.

Activity tip: *With older kids, you can use this toy for a playful game of "I Spy." Tell the child you spy an animal that has four legs and barks. Child must find and push the dog button. Switch roles and have the child make up the riddles while you find the animal.*

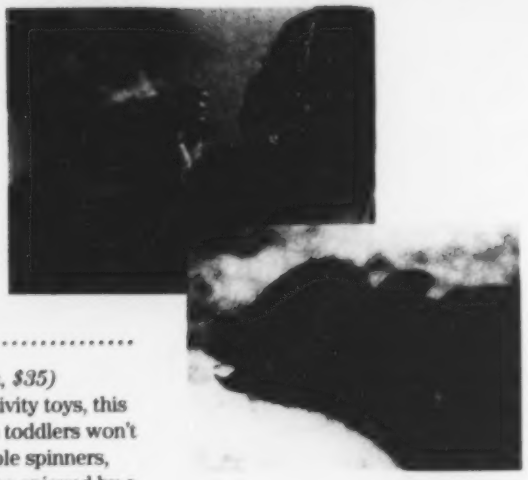
Or play "Who said that?" by putting a towel over the ball, pushing a button and asking the child to identify the animal who makes that sound.

You can also build auditory memory and sequencing skills with "Play what I play." Push buttons corresponding to two animals and have the child push the same buttons in the same order. Build up to sequences of three or more.

746

Sounds Around Video *(BoPeep Productions, $19.95)*
This live-action video features children exploring the musical, mechanical, animal and human sounds of everyday life. Cast is multi-cultural and includes a child with Down syndrome. Besides being fun, this video fosters sound awareness and auditory discrimination. It also helps a child build a vocabulary to describe the sounds he or she hears.

Activity Tip: *Without using anything but hands, feet, mouth and other body parts, how many different sounds can you and your play partner make?*



Play About Walker *(Little Tikes, $35)*
More stabile than most push-about activity toys, this sturdy toy leaves enough foot room so toddlers won't trip on the softly clicking wheels. Simple spinners, clackers and other activities can also be enjoyed by a baby who can sit up.

Adaptation idea: *For added sensory interest, or for a child with visual impairment, add textures to the push handle and activity panel.*

Activity tip: *Older tots will like rolling this back and forth or using it as a tunnel through which a smaller vehicle or ball can be rolled.*

Little Smart Table Talk
(V-Tech, $39.99)
You can personalize this electronic activity table by putting photos of Mom and Dad behind the peek-a-boo door slide. There are musical notes, a chime roller and plenty of easy-to-activate interactive buttons. This table needs little in the way of adaptation for younger kids. Tots will enjoy seeing the results of their actions. Preschoolers can build auditory memory skills and language with various games.

Activity tip: *Play an "I Spy" button game by giving your child a clue—"I spy a button that says 'woof, woof.'" Let the child try to find the button with the dog. Once your child knows the sounds on the toy, play the game with "no peeking." The first player listens without looking while the second touches one button. Based on the sound, the first player must identify the button.*

Sesame Street Spin Around Play Park *(Playskool, $25)*
Children with differing abilities enjoy this easy-to-activate merry-go-round and Ferris wheel that produces good sound and action with the push of a big plunger. Only the Elmo figure is removable; this avoids the frustration of having too many pieces to manipulate.

Adaptation ideas: *Glue fabric textures onto plunger for children with visual impairments. The base of this toy fits a wheelchair tray and can be attached with suction cups.*

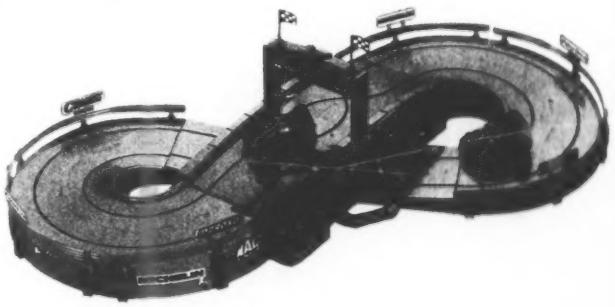
Activity tip: *This toy can help children work on concepts like start-stop, in-out and up-down. It may also teach them to take turns or play side by side. For extra play interest, a puppet on your hand can be one of the turn takers.*

Other soft toys can "ride" on the merry-go-round; to keep them from flying off when the plunger is pushed, add Velcro dots to their undersides and the insides of merry-go-round seats.

747

PRESCHOOL & EARLY SCHOOL YEARS

Table Toys *($69-299)*
The Table Toys company makes a variety of play tables for building with **Lego** or **Duplo** blocks. Their standard tables are 20" high to accommodate a stool or chair. Their newest model comes with adjustable legs which can make the surface high enough for a wheelchair. While the standard table has a storage bag in the middle, the new table uses cut-outs and bags in the corners so children don't have to reach as far. Building with colorful plastic Duplo and Lego blocks is fun for most children; it may also enhance color-matching, counting and size-discrimination concepts.



Radio-Control Raceway *(Fisher-Price, $79.95)*
This is a welcome new choice for kids who can't go chasing after a radio-controlled car or manipulate the small buttons on a standard racing set. This radio-controlled raceway has two chunky cars that can zip along the track which comes complete with under- and overpasses. A large single button controls each vehicle. Along with fun, this toy can build eye-hand coordination. It doesn't look babyish, although it is much easier to operate than typical racing sets.

Adaptation ideas: *Controller button can be covered with Velcro and used by a child who is wearing a Velcro mitt. For more control, tape the button to a fixed surface. Cars can be set to go at two different speeds for beginners and more skilled drivers.*

Adaptive Equipment for Dolls With Disabilities
(Lakeshore Learning Materials, $18.50 and up)
Now your child's favorite 15–16" doll can be fitted with realistic, doll-sized adaptive equipment. Choose from:
- Walker & accessory bag ($33.50)
- Two leg braces and two forearm crutches ($29.50)
- Wheelchair ($44.50)
- Guide dog, harness & cane ($18.50).

Press 'N Dress Fashion Doll
(Constructive Playthings, $29.95)
The Press 'N Dress Fashion Doll, now available in an African-American version, is the modern version of that favorite toy of yesterday—the paper doll. Each 13" fabric-covered doll comes with six Velcro-backed, cloth outfits that "slip on" with the press of a finger. Three additional sets of three outfits each are available ($14.95 each).

Mickey Press 'N Dress Doll *(Pockets of Learning, $30)*
Both boys and girls will enjoy playing with Mickey Mouse, another version of the Press 'N Dress doll. The Mickey doll uses Velcro-backed clothes that are easy to change. Wardrobe, stand and doll are stored in a zip-up carrying case.

748

Radio-Control Bubble Fire Truck *(Tyco, $30)*
A single button makes this fire truck go forward and then turn. It has flashing lights, but no annoying sounds. If you "gas it up" with bubble solution, it leaves a trail of bubbles as it moves. This toy will be very easy for most children to operate with no adaptations.

Little Tikes Place Wheelchair and Ramp *(Little Tikes, $12)*

The **Little Tikes Place** *($70)* is a big, open doll house ready for dramatic role-play. Chunky furniture is easy to manipulate, and so are the family figures. Add the wheelchair and ramp to make this doll house accessible!

Little Smart Driving School *(V-Tech, $39.95)*
All the fun of a steering wheel with electronic horn and other automotive sounds. It also includes a telephone and typewriter keyboard that says every letter a child presses for plenty of auditory feedback and reinforcement. The toy has a friendly quiz mode that will be fun for kids who are learning the names of letters.

Activity tip: *Play "Find the sound I'm saying"—"Can you find the letter that you hear at the beginning of these words: monkey, mommy, mountain?" Or, for older kids who are working on alphabetical order—"Can you find the letter that comes after 'T'? Before 'G'?"*

Talk 'N Dress Baby Bop *(Playskool, $34)*
Children who are working on dressing skills and following directions will enjoy buttoning, snapping and helping to dress Barney's popular pal, Baby Bop, who talks when her "belly" is squeezed. For a child with visual impairment, Baby Bop has a variety of textures—velour, fuzzy fur, satin and cotton.

Adaptation idea: *For children who cannot squeeze the doll's middle to make her talk, the sound box can be removed and placed on a table where it will respond to a touch.*

The Oppenheim Toy Portfolio is an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS; *it also publishes a quarterly newsletter. Both publications include useful sections on adapting products for kids with special needs. These sections are done in conjunction with the National Lekotek Center, a nonprofit organization serving special needs children and their families (See page 46).*

For more information, contact the Oppenheim Toy Portfolio, 40 E 9th Street, Suite 14M, NY, NY 10003, (800) 544-8697.

749

TOYS

Lekotek Puts Possibilities into Play

by Julie Morse and Wayne B. Smith

Sometimes, children with disabilities miss out on the fun and games of childhood. Parents, teachers and friends may mistakenly assume that children with disabilities cannot participate in the same activities as other kids. Or parents may be so absorbed in getting a child to appointments for special services that they simply forget to make play a priority.

That's why a special education teacher founded the National Lekotek Center in 1980—to provide children who have mental, physical and emotional disabilities with opportunities to play, learn and, most importantly, to have fun.

The first Lekotek center was modeled after a similar program in Sweden, where the word "lekotek," loosely translated, means "play library." Today, in addition to its national headquarters in Evanston, Illinois, Lekotek serves many hundreds of children through more than 50 affiliate centers in 20 states (and one in South America). Many Lekotek programs are offered on a sliding-fee scale, with scholarships often available. For Lekotek centers that do not offer sliding fees, yearly membership costs $50–180 a year.

Joey Sittler, 2, plays with a new toy at the National Lekotek Center in Evanston, Illinois. Joey has multiple disabilities. Photo: Hans Sittler.

Lekotek offers a family-centered approach to play. Children with special needs—along with their parents, siblings and sometimes, grandparents, other caregivers and neighborhood friends—attend monthly play sessions. Specially-trained "Lekotek leaders" introduce children to toys, games and computer software that are appropriate and challenging for their developmental level.

If necessary, toys are adapted to allow the child with a disability to use them independently. For example, a child with only limited use of his arms might not be able to operate a battery-propelled car with a control button requiring fine-motor skills like the flick of a finger. But when the car is connected by wire to a Velcro-fastened wrist band that houses a special "flip switch," the child only has to flip his wrist over to make the car move. In this way, the child experiences all the fun of a battery-operated toy while refining motor skills that will help him in other areas of life as well.

After a play session is finished, children are loaned their favorite playthings to take home for the next month. Nationwide, Lekotek toy libraries have more than 50,000 toys available to children and families. Participating families appreciate the cost savings of having access to a wide range of appropriate play materials for their children.

Lekotek's Compuplay program, available at 21 locations nationwide, also offers individualized computer training and playtimes using software appropriate to an individual child's developmental level with adaptive technology as needed. Some centers loan computers and software. Costs for Compuplay sessions range from $30–200 depending on the length and type of session and whether the particular program is subsidized by an outside agency.

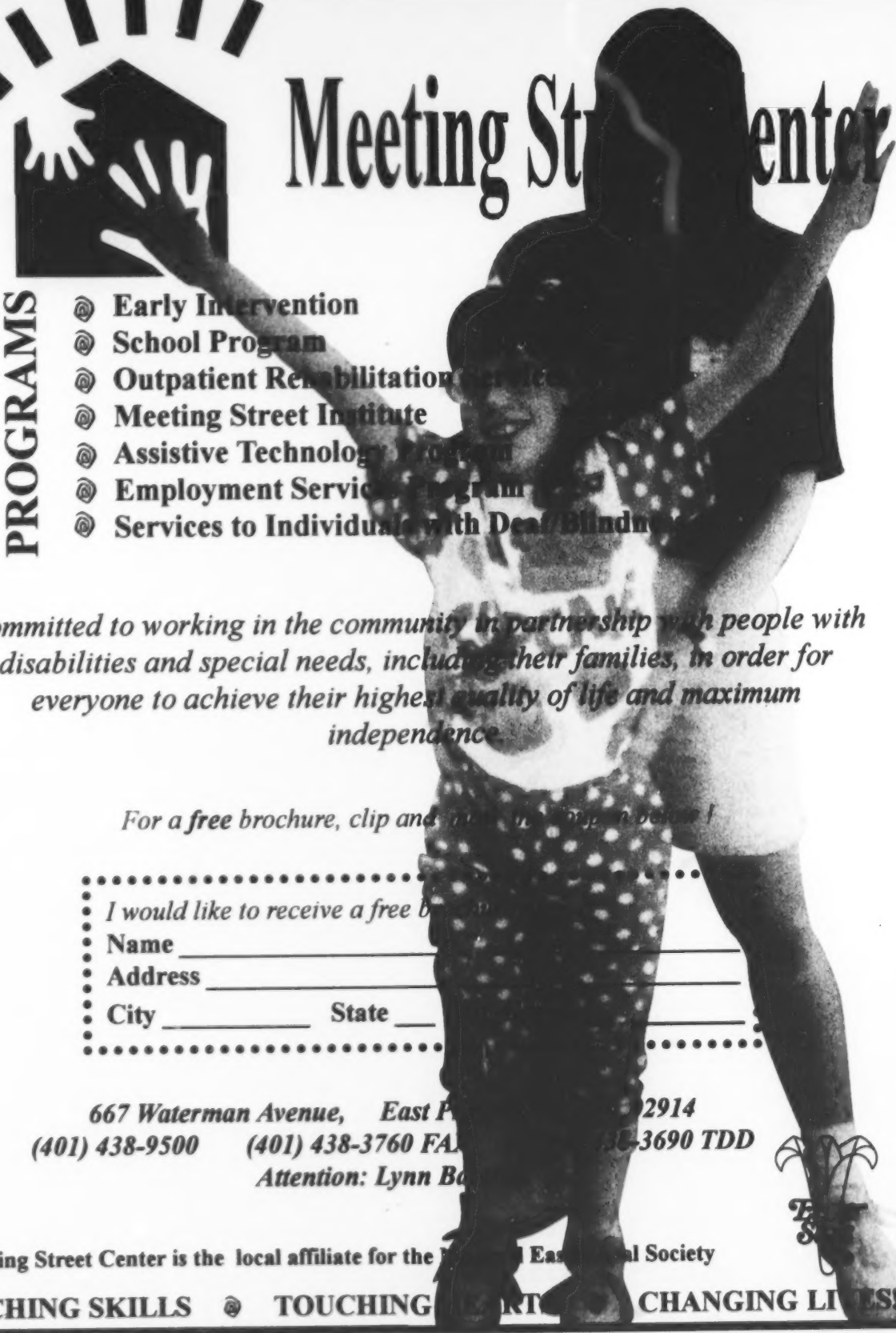
Lekotek offers special programs, too, like summer computer camps, ability-integrated play groups, preschool inclusion assistance and various family support services. In addition, year-round training programs are offered to teachers, parents and daycare providers. Toy-building manuals and videos are also available. Call (800) 366-7529 for a free catalog.

Today, the Lekotek movement is growing rapidly as parents express the need for Lekotek services in their own communities. The National Lekotek Center offers some basic guidelines for parents and professionals interested in starting a new Lekotek program:

- *Contact the National Lekotek Center* at (800) 366-7529, or write to 2100 Ridge Ave., Evanston, IL 60201, for the new "Lekotek Start-up Kit" ($15, covers duplication and shipping) which gives a step-by-step account of how to start a Lekotek Center in your community.
- *Contact other parents, professionals and community leaders* and tell them about the Lekotek program. Once you have a few individuals willing to advocate for the program, a community needs assessment can be done to determine whether there would be a demand for Lekotek services.
- *Contact community organizations* such as the National

750

Meeting St[illegible]enter



PROGRAMS

- Early Intervention
- School Program
- Outpatient Re[illegible]bilitation
- Meeting Street Institute
- Assistive Technology
- Employment Servic[illegible]
- Services to Individuals with Deaf/Blindn[illegible]

Committed to working in the community in partnership with people with disabilities and special needs, including their families, in order for everyone to achieve their highest quality of life and maximum independence.

*For a **free** brochure, clip and [illegible]*

I would like to receive a free b[illegible]

Name _____

Address _____

City _____ **State** ___

667 Waterman Avenue, East P[illegible]2914

(401) 438-9500 (401) 438-3760 FA[illegible]3690 TDD

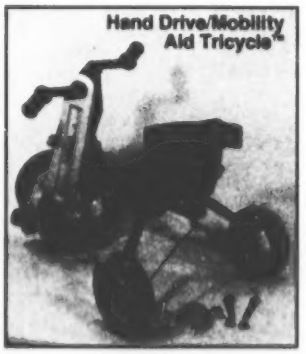
Attention: Lynn Ba[illegible]

Meeting Street Center is the local affiliate for the [illegible] Eas[illegible]l Society

TEACHING SKILLS ◉ TOUCHING [illegible]RT[illegible] CHANGING LI[illegible]S!

SEE OUR ***NEW*** AND ***EXPANDED***
CATALOG
FOR THESE ITEMS AND MORE

PLEASE ASK CUSTOMER SERVICE ABOUT OUR . . . ☐ Free Catalog with 100 plus products & accessories ☐ Trial Use Program ☐ Lease/Rentals ☐ Factory Outlet Store ☐ One Year Warranty ☐ How To Order Direct or via an Authorized Dealer



Consumer Care Products Inc.
810 N. Water St., P.O. Box 684
Sheboygan, WI 53082-0684
Tel: 414-459-8353 FAX: 414-459-9070
Since 1978

Circle # 109

Easter Seal Society affiliates, United Cerebral Palsy centers, schools, libraries, hospitals or civic groups, and propose the addition of a Lekotek Center to their existing services.

• *Attend a Lekotek "Leader Training Seminar."* Twice a year, the National Lekotek Center in Evanston, Illinois hosts intensive certification training seminars. The training dates in 1995 are February 6–10 and July 10–14. Contact the National Center at 1-800-366-7529 for details on training and certification requirements.

Lekotek and Compuplay Sites

(L=Lekotek, C=Compuplay)

ARIZONA

Arizona Easter Seal Society Compuplay (C)
Easter Seal Society for Disabled Children and Adults of Arizona
903 N 2nd St
Phoenix, AZ 85004
(800) 626-6061

Children's Lekotek and Compuplay of Phoenix (L, C)
Southwest Human Development
3033 N 24th St
Phoenix, AZ 85016
(602) 956-2711

Easter Seal Lekotek of Southern Arizona (L)
Arizona Easter Seal Society
5740 E 22nd St
Tucson, AZ 85711
(602) 745-5222

CALIFORNIA

Easter Seal Society of the Bay Area Lekotek (L)
Easter Seal Society of the Bay Area
2645 Pleasant Hill Rd
Pleasant Hill, CA 94523
(510) 939-7353

Lekotek Family Resource Center (L, C)
2701 Cottage Way, #27
Sacramento, CA 95825
(916) 979-1121

Lekotek of San Francisco (L)
The Easter Seal Society of the Bay Area
6221 Geary Blvd
San Francisco, CA 94121
(415) 752-4888

Easter Seal Lekotek (L)
Easter Seal Society of the Tri-Counties
977 Pismo St, Box 795
San Luis Obispo, CA 93406
(805) 543-4122

COLORADO

Lekotek of Northern Colorado (L)
Foothills Gateway Rehabilitation Center
301 Skyway Dr
Fort Collins, CO 80525
(303) 226-2345

DELAWARE

Delaware Curative Lekotek (L, C)
Delaware Curative Workshop
1600 Washington St
Wilmington, DE 19802
(302) 656-2521

GEORGIA

Lekotek of Georgia (L, C)
1955 Cliff Valley Way, Ste 102
Atlanta, GA 30329
(404) 633-3430

Marcus Center Lekotek (L)
Marcus Center
1605 Chantilly Dr
Atlanta, GA 30324
(404) 727-5437

Egleston Gwinnett Lekotek (L)
Egleston Children's Health Center
3802 Satellite Blvd
Duluth, GA 30136
(404) 497-9179

Lekotek of Georgia-Rome (L)
52 Twickenham Rd
Rome, GA 30161
(706) 234-2884

ILLINOIS

Easter Seal Lekotek of Southwestern Illinois (L)
Easter Seal Society of Southwestern Illinois
1719 Washington Ave, Box 219
Alton, IL 62002
(618) 462-8897

Easter Seal Lekotek of Southwestern Illinois (L)
United Cerebral Palsy
PO Box 100
Belleville, IL 62221
(618) 277-4895

East Central Illinois Lekotek (L)
1304 W Bradley Ave
Champaign, IL 61821
(217) 351-1008

Lekotek in West Humboldt Park (L)
c/o Chicago Commons
1633 N Hamlin
Chicago, IL 60647
(312) 772-0900

El Valor Lekotek (L, C)
El Valor
1951 W 19th St
Chicago, IL 60608
(312) 997-2029

Lekotek at Speed (L)
1125 Division St
Chicago Heights, IL 60411
(708) 481-6740

752

USA Toy Library Association

The USA Toy Library Association (USA-TLA) is a national network of nearly 400 toy lending libraries serving children with and without disabilities. Depending on the particular program, families may borrow both commercially-available and specially-adapted toys. Yearly costs for using toy libraries range from $0–35.

USA-TLA assists individuals and organizations in establishing and promoting toy libraries in local communities. The organization also distributes information on toy repair and discounts, and provides research material on play, toys and early learning. In addition, they offer books, videos and a quarterly newsletter.

For information on any of these services, or to locate the toy library nearest to your home, write to USA-TLA, 2530 Crawford Ave., Suite 111, Evanston, IL 60201.

Lekotek of Evanston (L, C)
National Lekotek Center
2100 Ridge Ave
Evanston, IL 60201
(708) 328-0001

Lekotek in Flossmoor (L)
Good Shepherd Center
2220 Carroll Pkwy
Flossmoor, IL 60422
(708) 957-5700

WSSRA Lekotek (L)
West Suburban Special Recreation Association
2915 N Maple St
Franklin Park, IL 60131
(708) 455-2100

Galesburg Public Library Lekotek Center (L)
Galesburg Public Library
40 E Simmons St
Galesburg, IL 61401
(309) 343-5358

Southern Illinois Lekotek (L)
112 N Gum
Harrisburg, IL 62946
(618) 253-5581

Easter Seal Lekotek-Kankakee (L)
Easter Seal Society of Mid-Eastern Illinois
895 S Washington Ave, Box 84
Kankakee, IL 60901
(815) 932-0623

Parents Infant Center Lekotek (L)
Special Education District of Lake County Parent-Infant Center
1585 N Milwaukee Ave, Ste 4
Libertyville, IL 60048
(708) 549-0662

DuPage/West Cook Lekotek Center (L)
DuPage/West Cook Regional Special Education Association
1500 S Grace
Lombard, IL 60148
(708) 629-7272

Lekotek Center Of West Central Illinois (L)
Easter Seal Foundation
1504 13th Ave
Moline, IL 61265
(309) 762-9552

Easter Seal Lekotek Center-Normal (L)
Easter Seal Society
206 S Linden, Ste 4A
Normal, IL 61761
(309) 452-8074

Southwest Cooperative Compuplay (C)
Southwest Cook County Cooperative Association for Special Education
6020 W 151st St
Oak Forest, IL 60452
(708) 687-6495

LaSalle County Easter Seal Lekotek Center (L)
LaSalle County Easter Seal Society
1013 Adams St
Ottawa, IL 61350
(815) 434-0857

Easter Seal Lekotek Center-Peoria (L)
Easter Seal Society
320 E Armstrong Ave
Peoria, IL 61603
(309) 671-5884

Rockford Lekotek Center (L)
Fairview Early Education Center
512 Fairview Ave
Rockford, IL 61108
(815) 229-4230

Clearbrook Lekotek (L, C)
Clearbrook Center for the Handicapped
3705 Pheasant Dr
Rolling Meadows, IL 60008
(708) 392-2812

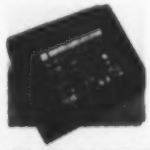
Lekotek at McKinley (L)
850 E 170th St
South Holland, IL 60473
(708) 333-7814

You Asked DynaVox To Do Even More...

"I want to tell a story."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at 1-800-344-1778.



We Hear You.

TECHNOLOGY INC.
Circle # 68

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 44

UCP of Land of Lincoln Lekotek Center (L)
United Cerebral Palsy of Land of Lincoln
130 N 16th St
PO Box 19494
Springfield, IL 62794-9494
(217) 525-6522

Tri-County Lekotek (L)
Northwestern Illinois Association
3807 Woodlawn
Sterling, IL 61081
(815) 625-7931

Lekotek Family Resource Center-Tinley Park (L)
Arbor Park School District 145
Kimberly Heights School
6141 Kimberly Dr
Tinley Park, IL 60477
(708) 532-6434

INDIANA

Lekotek of Indianapolis (L, C)
Crossroads Rehabilitation Center
4740 Kingsway Dr
Indianapolis, IN 46205
(317) 466-2018

Lekotek-Open Door (L, C)
United Health Services
711 E Colfax Ave
South Bend, IN 46617
(219) 233-4366

IOWA

Lekotek-YWCA (L, C)
318 Fifth St, SE
Cedar Rapids, IA 52401
(319) 365-1458

KANSAS

Children's Center Compuplay (C)
Early Childhood Development Center
94 Lewis Dr
Hays, KS 67601
(913) 625-3257

LOUISIANA

Compuplay Resource Center (C)
Easter Seal Society of Louisiana for Children and Adults with Disabilities
4937 Hearst Plaza, Ste 2-L
Metairie, LA 70001
(504) 455-5533

MICHIGAN

Detroit Institute Compuplay Resource Center (C)
Detroit Institute for Children
5447 Woodward Ave
Detroit, MI 48202-4009
(313) 832-1100, ext 231

The Arc Lekotek (L)
The Arc of Northwest Wayne County
26049 Five Mile Rd
Redford, MI 48239
(313) 532-8524

MINNESOTA

Courage Center Lekotek (L, C)
Courage Center
3915 Golden Valley Rd
Golden Valley, MN 55422
(612) 520-0417

NEW JERSEY

Shirley Eves Center - Lekotek (L)
10th & Vine Sts
Millville, NJ 08332-0787
(609) 825-5840

NEW YORK

The Lekotek Center (L)
East Rockaway Public Library
477 Atlantic Ave
East Rockaway, NY 11518
(516) 593-1222

OHIO

Lekotek of Greater Cleveland (L)
The Achievement Center for Children
11001 Buckeye Rd
Cleveland, OH 44104
(216) 795-7100

Compuplay (C)
United Cerebral Palsy of Greater Cleveland
2141 Overlook Rd
Cleveland, OH 44106
(216) 791-8363

PENNSYLVANIA

Lekotek of United Cerebral Palsy of Northeastern Pennsylvania (L)
UCP of Northeastern Pennsylvania
423 Center St
Clarks Summit, PA 18411
(717) 587-5892

Children's Lekotek of Southeastern Pennsylvania (L, C)
The Developmental Center for Autistic Children, Thomas Jefferson University Hospital
3965 Conshohocken Ave
Philadelphia, PA 19131
(215) 878-3400 ext 11

PUERTO RICO

Centro Lekotek (L)
Sociedad de Education y Rehabilitacion de Puerto Rico
PO Box 360325
San Juan, PR 00936-0325
(809) 767-6710

TEXAS

Children's Lekotek Center of Houston (L)
United Cerebral Palsy of Greater Houston
1415 California St
Houston, TX 77006-2693
(713) 522-1051

UTAH

Easter Seal Society Compuplay of Utah (C)
Easter Seal Society
254 W 400 S, Ste 320
Salt Lake City, UT 84101-1830
(801) 531-0522

VIRGINIA

George Mason University Compuplay (C)
Center for Human Disabilities
4400 University Dr, MS1F2
Fairfax, VA 22030
(703) 993-3670

WISCONSIN

Marshfield Children's Lekotek Center (L)
Saint Joseph's Hospital
611 St Joseph Ave
Marshfield, WI 54449-1898
(715) 387-7885

Switch on the Fun

The Scanning 2-XL™ Talking Robot. Innovative, interactive, educational—and fun. Most importantly it is accessible using a single switch through scanning. Developed with the exceptional child in mind, it's the perfect playmate for learning and entertainment. The 2-XL tells stories and jokes, plays your child's favorite audio cassettes, asks questions and waits patiently for your child to scan and select the correct answer. A great gift for the holiday season. Order soon, as quantities are limited. Call or fax InvoTek today for a free catalog and pricing.

INVOTEK CORPORATION
700 W. 20th St.
Engineering Research Center
Fayetteville, AR 72701
(fax) 501-575-7446

1-800-576-6661
Providing Independence Through Technology

2-XL™ is a registered trademark of Tiger Electronics.

Circle # 211

754

NEW IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY, NO LUMPING.

To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the ... selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information about DIAFOODS THICK-IT, may be purchased, call... (800) 333-0003.

Circle # 169

755

NEW PRODUCTS: TOYS

RUBBER JACKS & BALLS

Metal and plastic jacks that hurt little hands can now be replaced with slightly oversized jacks made of rubber! These colorful jacks give under pressure so children can pick them up safely. Eye-hand coordination and grasping skills can be enhanced with these eight jacks and rubber ball.

Chime Time, Atlanta, GA 30340-1562

Circle # 270

K'NEX

Twenty-two basic shapes with an infinite number of possibilities. The K'Nex color-coded construction sets let children build anything from simple flat designs to three-dimensional models and vehicles. The interlocking pieces snap together and can even be connected using only the sense of touch. Shapes hold the attention of all children. Sets available for cars, trucks, flying saucers, roller coasters and more. Edges are rounded for safety.

Connector Set Toy Company, Hatfield, PA 19440-0700

Circle # 271

REALITY DOLLS & WHEELCHAIR

The Reality Dolls are soft, washable dolls designed to build the self-esteem of children with disabilities and to increase awareness of disabilities for children without disabilities. The dolls are featured with hearing aids, crutches, prostheses and white canes.

A doll-size wooden wheelchair is also available.

Antoni Toys and Products for the Physically Challenged, Portland, OR 97214

Circle # 272

MODULAR FRAME: ADJUSTABLE WEDGE

This oak board tilts up to 90 degrees for full access to its three single-activity modules. Each module is Velcro mounted for removal and repositioning. Activities include tactile, visual, auditory and/or fine motor skills—pick from a list of activity options to suit your child's abilities and interests!

Danmar Products, Ann Arbor, MI 48103

Circle # 273

SENSY BALLS

These bright yellow, inflatable balls are covered with tiny rounded protrusions that are sure to stimulate tactile sensations. Available in three sizes for various types of recreation and therapeutic play. The smallest are sold in pairs and are only 10 cm in diameter—perfect for little hands.

Ball Dynamics International, Inc., Denver, CO 80202

Circle # 274

INTELLIPICS

This educational software program allows adults to create activities for children to explore the fun of learning. Graphics, quicktime movies, animation, recorded sound and synthetic voices are used to teach shapes, colors, numbers and letters. Animals, music, dinosaurs and more help to keep children interested. For use on Macintosh computers.

IntelliTools, Inc., Richmond, CA 94804

Circle # 275

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

756

Sibling Concerns

by Donald J. Meyer

This article is an excerpt from SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS (Paul H. Brookes, 1994). This is the second of four excerpts EXCEPTIONAL PARENT will publish. SIBSHOPS is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.

Given that most brothers and sisters harbor a wide range of feelings toward their siblings, it is not at all unusual to learn that siblings of people with special needs also experience ambivalent feelings about their brothers and sisters. After all, a relationship in which one sibling has a disability or illness is still a sibling relationship. Adding a special need to the equation appears to enhance the inherent ambivalence…

ILLUSTRATIONS BY CARY HELLQUIST

It is difficult to make generalizations about siblings who have brothers and sisters with special needs, because this is only one aspect of their lives. Disabilities and illnesses affect people from all walks of life, and siblings will experience these conditions in innumerable ways. However, in listening to brothers and sisters, we hear recurring themes, despite the diverse backgrounds of these siblings… No one brother or sister will experience all of the concerns discussed below, but all will share some…

Overidentification:

Overidentification occurs when a sibling wonders whether he or she shares—or will share—a sibling's problem…The risk of overidentification is one of the many reasons that brothers and sisters need accurate information about their siblings' disabilities and illnesses. Information that may be obvious to adults may not be to children. For instance, younger children need to know that they cannot "catch" their siblings' disability…

Embarrassment:

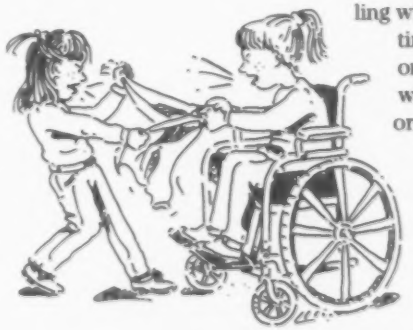
A sibling with a disability or illness can be a source of embarrassment for typically-developing brothers and sisters…

Developing strategies to spare a typically-developing child embarrassment first requires analyzing the cause of the embarrassment. Is it something that can be changed, such as an age-inappropriate bib on a sibling who drools, or a behavior, such as singing during the sermon at church, that could be changed through a carefully considered behavior program? If changeable, then the family can work toward decreasing the sibling's embarrassment and improving the life of the person with special needs at the same time.

However, it is equally likely that the source of embarrassment is something about which little can be done. In these instances, there are two strategies parents may wish to consider. First, they should remember that most children go through stages when they are easily embarrassed, and these experiences may be unavoidable.

Early adolescents have a particularly strong need to conform. It can make a teenager miserable to be seen with her parents, much less with a sister who looks and acts differently… During this time of raging conformity, the best strategy may be to give the typically-developing child "space," psychological and otherwise. Given permission to walk on the other side of the shopping mall or attend a different church service, most siblings will eventually re-integrate their brother or sister…

A second strategy is to acknowledge the embarrassment… Denying siblings "permission" to be embarrassed by their sibling (as in "He's your brother; you shouldn't be embarrassed by him!") is more likely to invoke guilty feelings than to reduce embarrassment. It also will send a message that children cannot bring their concerns to their parents. Acknowledging that a sibling with special needs is sometimes difficult to live with not only reflects reality (after all, what sibling—special needs or not—is always easy to live with?), but it also sends a message that brothers and sisters can feel free to talk about their feelings with their parents…



Luckily, for most siblings, embarrassment is transitory… Most brothers and sisters have a remarkable ability to re-frame difficult situations in a more positive light…

Guilt:

…Siblings of individuals with special needs are far more likely to experience guilt than siblings of individuals with-

757

Free Children's Book

Pediatric Projects, Inc.

a nonprofit group advocating quality mental health practices for children and families in health care

will send you **free**

- a popular book for children on health care
- flyers on medical toys and books you can buy at low cost
- a sample issue of our newsletter, **Pediatric Mental Health®**

Send your name/address/zip, with $2 (postage/handling), to

Pediatric Projects, Inc.
PO Box 57-1555
Tarzana CA 91357

Circle # 263

E TUNED-IN, TURNED-ON BOOK
About Learning Problems
-Revised Edition-

Help your child learn how to work around learning disabilities

In this best selling self-help guide written directly to adolescents and teens, author Marnell Hayes, Ed.D., takes a positive and practical approach to helping kids capitalize on their individual learning style.

The content of the new edition now includes new study tips, a new glossary, and more 'homework' for parents and teachers to help them understand what a child with learning difficulties needs them to know.

TUNED-IN, TURNED ON BOOK About Learning Problems
6x9" softcover, 163 pp. #090-1 $10.00
PREPAID: Add $2.50 s/h BILLED: Add 10% s/h (min. $2.50)
California residents add sales tax.

ACADEMIC THERAPY PUBLICATIONS
20 COMMERCIAL BLVD. NOVATO, CA 94949-6191
1 (800) 422-7249 Fax: (415) 883-3720

Circle # 244

out special needs... Brothers and sisters may feel they caused their siblings' disability; they may experience survivor's guilt; they may feel guilty about their own abilities or about harboring less-than-charitable feelings about their siblings.

Isolation, Loneliness and Loss:

...A sibling's disability or illness can cause brothers and sisters to experience various feelings of loss and isolation.

Especially if there are only two children in the family, typically-developing siblings may miss having a brother or sister with whom they can seek advice, or share their thoughts, hopes and dreams. They may also long for the rough-but-loving relationship many siblings share...

When parents are consumed with a child's disability or illness, typically-developing brothers and sisters can feel neglected and isolated from their parents. These feelings are especially keen during times of stress for the family, such as diagnoses or hospitalizations...

Of course, when a child is facing a health or developmental crisis, it may be impossible for parents to meet all their children's needs for emotional support. During trying times, many families enlist the support of a favorite relative or adult friend who provides the healthy child with time, attention and an "open ear."

Donald J. Meyer is the director of the Sibling Support Project at Children's Hospital and Medical Center in Seattle. Don is the younger brother of two siblings who have epilepsy. He is married and the father of four children. His book, SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS, details the program that won the 1992 National Award for Innovation from the Association for the Care of Children's Health.

758

The Biggest Game

by Bill Abbott

One afternoon, I was reading articles from EXCEPTIONAL PARENT *magazine to my husband, Bill. When I finished the* FATHERS' VOICES *section, I looked up to see tears rolling down my husband's rugged face. "It's a good thing," he said, and walked out of the room, seemingly embarrassed by his show of emotion.*

Several hours later, I was intrigued to find my husband frantically writing away in a tattered notebook. Our two children kept vying for his attention, but Bill was completely focused on the project at hand. Finally, he took a deep breath and pushed his chair back from the table. Handing me the notebook, he said, "This is my story."

My husband has never been big on words or expressing his feelings. After reading his story about his relationship with our son, Gregory, tears rolled down my face also.

"This is wonderful!" I said. "Let me send it in to FATHERS' VOICES."

Bill told me that he didn't care if I sent it in or not. He said it just felt good to express his feelings.

I have enclosed my husband's story. I will also keep it for Gregory to read when he is older.

—Cara Abbott

While waiting for my child to be born, I was like any other expectant father. I dreamed of the activities I would share with my firstborn son. As a young child and teenager, my life had revolved around sports. I dreamed about teaching my boy to throw a curve ball and catch a football.

I will never forget the day Gregory was born. When the doctor said, "It's a boy," I felt like I was walking on air. Then, reality knocked me to the ground. My son had sustained a brain injury after an excruciatingly long labor and nightmarish forceps birth. He was rushed to a larger hospital where he spent the next two weeks in the neonatal intensive care unit. At least he was alive, but I felt completely powerless to help him.

As the months went by, we began to realize that Gregory was not doing the same things as other babies his age. After many visits to specialists, we were given a diagnosis of cerebral palsy.

I am an over-the-road truck driver. I was in Oklahoma City, Oklahoma the night my wife, Cara, gave me the news of Gregory's diagnosis. I was angry at the world. I prayed to God and to my late father. I asked, "Why has this terrible thing happened to me?"—as if I were the one with cerebral palsy.

Now, four and a half years later, the son is teaching the dad. Gregory is my son, but he is also my best friend. There are parts of me that only he knows and understands.

Gregory has more heart and gumption than any ball player I have ever seen. The cerebral palsy affects Gregory's right arm and leg, his speech and his balance. As I watch him try to walk and use his weak arm, I have to restrain myself from helping him. In the long run, I know it will be better if he does things by himself.

Bill Abbott, 35, has traveled across the United States and Canada as an over-the-road truck driver. He lives in Columbia, Missouri with his wife, Cara, and sons Gregory, 5, and Patrick, 8 months. He also has a daughter, Jennifer, from a previous marriage.

759

5 Models Available Now

The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185

Innovative Products, 830 S. 48th, Grand Forks, ND 58201

Photo used by permission Hedstrom Corp. of Bedford, PA

Circle # 42

© 1991 RSI Patent Pending

The Baby Jogger®

Mobility and comfort combine for both parent and child! The ***Baby Jogger*** offers new models to suit a variety of special needs. Go anywhere with the ultimate all-terrain stroller. Travel over gravel, grass, curbs, even sand and snow with "The stroller for runners." Trips to the beach or park are easy with the smooth-rolling three wheel design. A variety of models available for children of all ages. **FREE BROCHURE.**

Racing Strollers Inc. P.O. Box 2189
Yakima, WA 98907 **(509)457-0925**

Safe, stable, endorsed by pediatricians.

Circle # 177

I could talk about my son all day. It is a big thrill for any parent to see a child take his first steps. But when your child wears ankle-foot orthotics and is two and a half years old, seeing him take his first step is a miracle.

I would gladly trade places with Gregory; I'd do anything to make his life easier. However, my son has shown me I don't have to worry about his future. I know he has the drive to accomplish whatever he decides to do.

I have always dreamed of being a coach. Well, I got my wish. Encouraging Gregory to become independent will be the biggest game I will ever coach. Teaching him to stand in one spot without taking a tumble, teaching him to successfully navigate the bathroom, teaching him to pull his pants down *and* back up again—these are much greater rewards than winning any Super Bowl or World Series.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

760

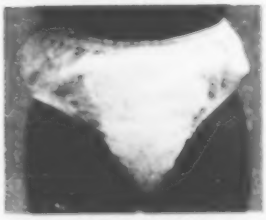
Introducing

WEAR•EVER™

THE FREEDOM TO GO WHEREVER YOU WISH℠

Wear Ever Boys: Mild to Moderate Incontinence. 8 oz. capacity.

Wear Ever Missy: Mild to Moderate Incontinence. 8 oz. capacity.



Wear Ever Pull-Up: For Severe Incontinence. 15 oz. capacity.

Introducing **WEAR•EVER**™. The first family of washable, reusable incontinence underwear that outperforms disposables.

The secret? **WEAR•EVER** underwear is made exclusively with Hypersorb™, a revolutionary fabric with extraordinary absorbency and quick-drying properties.

In fact, **WEAR•EVER** underwear holds up to 450cc of urine –15 ounces– without leakage, and that means greater comfort, confidence and freedom.

Plus, **WEAR•EVER** underwear can be washed up to 200 times without losing its absorptive powers. Which means you'll save at least $1,300* a year over disposables.

WEAR•EVER. All sizes. Lightweight. Fashionable. Environmentally-friendly. And guaranteed for one year or your money back.

To order, or for more information, please call:

1-800-550-4MOM

MasterCard VISA

Wear Ever Butterfly: For Severe Incontinence 15 oz. capacity.

TMI *HEALTHCARE PRODUCTS INC.*

307 Bacon Road • Rougemont NC 27572 • (919) 477-1387 • Fax (919) 477-2294

* Based on research by TMI.

Circle # 122

Back and forth, in and out of conventional hospitals and treatment programs. Some children's complex behavioral and emotional issues can frustrate and overwhelm professionals' ability to treat chronic diseases, brain injuries, or other medical conditions. Our unique medical and behavioral approach can break the cycle of repeated failures.

C U M B E R L A N D

Hospital for Children and Adolescents · 9407 Cumberland Road · New Kent, Virginia 23124 · 1-800-368-3472

Circle # 18

762

Step by step

Creating no-step entrances may be easier—and less expensive—than you think

by Eleanor Smith

This article was adapted from ENTRYWAYS: CREATING ATTRACTIVE, INEXPENSIVE NO-STEP ENTRANCES TO HOUSES *to give basic guidelines for adapting an existing home with no-step entrances.* ENTRYWAYS *provides in-depth instructions on how to build no-step entrances when building a new home.*

ENTRYWAYS, published by Concrete Change, costs $8. Concrete Change also offers BUILDING BETTER NEIGHBORHOODS, *a $24 video about why universally accessible housing is necessary and practical. Contact Concrete Change at 1371 Metropolitan Ave. S.E., Atlanta, GA 30316 or call (404) 378-7455 (voice) or Disability Action Center at (404) 687-9175 (TTY only).*

No-step entrances built with attractive materials and landscaping can be a well-integrated asset to the design of any house. The no-step entrance should be the entrance primarily used by family members and guests, both for convenience and for the symbolic welcoming tone. However, the lot's terrain is a relevant factor. For example, don't construct a no-step entrance in front if terrain realities make it a great deal easier to create an entrance at the side or back. In all cases, using the land to advantage is the key.

The no-step entrance must be a gentle slope, no steeper than 1:12—meaning one foot in rise per 12 feet in length. If a slope is too steep, it is unusable.

The slope can be steeper than 1:12 only if the rise is 11 inches or less.

The length of the sloped sidewalk, ramp or walkway that provides the no-step entrance often can be shortened by using the land. The elevation of the incline's starting point should be as close as possible to the elevation of its arrival point.

Access All Around

Eleanor Smith remembers being a teenager at a party in the '60s. Unable to get her wheelchair through the narrow bathroom door, she slid off the chair and prayed no one would see her scooting through the doorway in her fancy party dress.

Now, at 51, Smith is helping to lead the fight for barrier-free homes. Smith, founder of the Atlanta-based Concrete Change, says creating accessible housing for people with disabilities must go beyond adjusting only the homes of people with disabilities. All homes, she says, must be "visitable."

"The most important thing for visiting is being able to get in the house, and get through the interior doors," says Smith, who was paralyzed by polio at age three.

Unless children with disabilities have access to the homes of friends and relatives, Smith says, they're likely to miss out on many important childhood experiences.

"I know I was left out of certain things because of architecture, like the birthday parties because the mother didn't think she could handle me getting in the house," Smith recalls. Or like being stranded in a backyard while all her friends ran in the house to play. Or being able to visit only five stores in her hometown of Eureka, Illinois, because the other stores' entrances had steps.

Eleanor Smith in front of a row of Atlanta Habitat for Humanity houses, all of which have basic access.

Smith says people must demand that their homes be barrier-free—whether or not they know someone with a disability.

"Cost is not the issue," says Smith, refuting myths that barrier-free homes are too expensive to build. "The issue is habit—what builders are willing to do and what the public is willing to demand and ask for."

Although Concrete Change has no formal membership, Smith says hundreds of people around the country are either using its concepts or starting their own Concrete Change chapters.

"This is about action," Smith says. "If you walk away from a builder who won't build a wider bathroom, then you're a part of Concrete Change."

—*M.S.M.*

763

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle # 27

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

Whether it's a sidewalk, a bridge or a ramp, its surface should be level side to side so it does not tilt the user. Most building codes require railings if a structure is more than eight inches above the ground. If railings aren't required, 2×2s nailed along the outside edges of the ramp or walkway can prevent wheels from rolling off the side.

The route from the street or driveway to the no-step entrance must, like the incline or walkway, be no steeper than 1:12. Even when grading is done with access in mind, sometimes a steep lot requires a driveway much steeper than 1:12. In that case, someone can at least arrive by car or be helped up the driveway and then enter the house by means of a level or gentle slope leading from the driveway to the entrance.

Recommended Lengths for Low Rises

Rise	Length of slope or ramp
¼" or less	Acceptable threshold height; no slope necessary
1 inch	3 inches
2 inches	6 inches
4 inches	1 ½ feet
5 inches	2 feet
6 inches	3 ½ feet
7 inches	5 ½ feet
8 inches	7 feet
9 inches	8 feet
10 inches	9 feet
11 inches	10 feet
12 inches or more	1 foot per inch of rise

Unless the incline is extremely gradual (at least 20 feet long for every foot of rise), it must end in a level platform so that a wheelchair user can open the door without struggling to keep from rolling backward down the incline. A garage floor, sidewalk or porch can serve as the platform.

Ramps: Design Considerations

When designing a ramp, keep in mind:

- A ramp does not have to stick out at right angles from the house. Often the best route is a ramp that runs parallel to the side of the house and ends in a level platform as in the porch. A ramp parallel to the house is often the easiest way to take advantage of the natural lay of the land so that the ramp can be as short as possible and still be gentle enough.
- A ramp does not *have* to begin at the point closest to the wheelchair user's approach. The person can travel a few yards farther to get to the appropriate beginning point of the ramp. The ramp should generally start on the highest point of land near the entrance at which it is practical to construct a ramp.
- When evaluating the best place to add a ramp, ask: Can an existing porch rail be cut out? Can existing bushes be removed and replanted along the ramp?

Eleanor Smith is the founder of Concrete Change, an Atlanta-based volunteer organization fighting for universal basic access to houses.

764

Dental Care for Children with Disabilities

A Visit to the Dentist

by Steven P. Perlman

PART THREE

Regular professional cleaning and dental treatment are important for preventing dental problems. This is especially true for children with disabilities who may be at greater risk of dental disease because of oral conditions related to a specific disability, physical limitations which interfere with oral hygiene or the use of medications that may cause decreased saliva flow or gum inflammation. Children with disabilities may require more frequent dental visits than children who do not have disabilities—possibly four times a year depending on the child's needs.

Finding the Right Dental Office

Some dentists are trained to treat children with special needs. Call your local dental society—the number is in the phone book—for a referral to a nearby dentist who treats children with disabilities. Other resources are listed at the end of this article.

The dental office that you select should be "prevention-oriented." An office with this orientation will usually have a registered dental hygienist who specializes in preventing gum disease and tooth decay. The dental staff also should practice infection-control precautions for all patients, meaning dentists and hygienists should wear gloves, protective eyewear and masks.

Before making an initial appointment for your child, you may want to discuss the child's special needs with office staff. This is the time to talk about seating, positioning and access issues. You may want to ask if someone is available to assist you if necessary when arriving or leaving. You may also have questions about parking or public transportation. It is a good idea to visit the dental office by yourself, before the child's first appointment.

You may also want to ask for suggestions about preparing the child for a visit to the dentist. Usually, it helps to reduce fears of the unknown and increases cooperation when children know what to expect in a situation with a new professional.

Sometimes, Mom's lap is the best seat. This is one way a parent can provide gentle restraint along with a reassuring presence to help manage a small child's behavior during dental treatment.

The First Appointment

At the first appointment, the dental hygienist or dentist should take the child's complete medical and dental health histories. They need to know if the child is currently under a doctor's care. They also need to know about any medications the child takes on a regular basis.

After a health history is taken, a dental professional should give the child a thorough head-and-neck examination. This will include examination of the child's teeth and gums. If necessary— and possible—x-rays will be taken at this time.

Before any treatment is started, you should be told what was found during the exam, what treatment will be needed, how many appointments need to be scheduled and approximately how much it will cost. This is a good time to ask questions or voice concerns.

The dentist or hygienist should spend some time during the first appointment discussing ways to improve the child's oral health. The dental professional can advise about the child's needs, including nutrition, and can show you the best way to clean the child's teeth at home. The dentist may also recommend additional protection against cavities such as fluoride and sealant treatments. (Fluorides protect the sides of the teeth. Sealants are thin plastic coatings that cover and seal the

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to his private practice, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their "Special Athletes, Special Smiles" program. Dr. Perlman lives in Swampscott, Massachusetts.

765

chewing surfaces of the back teeth. Together, fluorides and sealants are highly effective against cavities. Sealants are used only on permanent teeth, so they are not recommended for children under the age of six.)

It is important that the office staff be "right" for your child. Make decisions based on the actions of the dentist, dental hygienist and other personnel in the office and the way the child reacts to these individuals. Does the dentist/hygienist:

- Allow time for the child to familiarize himself with the environment and become comfortable?
- Speak to the child appropriately—using simple language if necessary?
- Calm the child by using a pleasant, reassuring voice?
- Praise the child when praise is appropriate?
- Introduce actions, instruments and procedures slowly?
- Provide motivation to brush and cooperate at home?
- Appear confident and comfortable in his or her approach to the child?

Tips for Success

- When making an appointment, remind the office staff if special considerations are required due to your child's disability.
- Schedule visits at times when the child is least tired and less likely to be irritable.
- Call the office before you leave for your appointment to find out if the day's appointments are running on schedule. This can help avoid unnecessary waiting.
- Arrive on time.
- Be organized: Bring the names, addresses and phone numbers of other professionals involved with the child. Know the names and dosages of any medications the child is using.
- Don't feel embarrassed by the child's behavior or other aspects of his or her disability. Your child has the same right to good dental care as any other child.
- Ask questions about terms or

A father (foreground) holds his son's hand down while one hygenist provides additional restraint and another cleans the boy's teeth.

Berkshire Meadows

is a private, non-profit year-round residential school for children and adolescents who are developmentally delayed and may be multiply disabled.

We believe that everyone,no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, young people can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Functional Communication used for an advanced approach to behavior management

Associations with leading specialists and major medical centers throughout the country

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road, Housatonic,
MA 01236 (413) 528-2523

Circle # 6

766

A scientific breakthrough in dental hygiene

THE AUTOMATIC TOOTHBRUSH

ORALGIENE™ 767

The Science of Oral Hygiene

Call toll free to order 1-800-933-ORAL (6725)

VISA, MC, DISCOVER, AMEX, or send check or money order to:
Oralgiene USA, Inc.
421 North Rodeo Drive, Suite 15114
Beverly Hills, CA 90210

Circle # 219

procedures you do not understand.
- Provide information about previous procedures or techniques which have helped your child cooperate or made him less cooperative.

Helping Children Cooperate

Usually because they are fearful and/or do not understand why the dentist is doing things to them, children can have difficulty being cooperative—and this makes it difficult, or even impossible, to provide high quality dental care. Behaviors that may interfere include hyperactivity, resistive movements and refusal to open mouth or keep it open long enough. Some children become physically resistant to treatment; they may kick, scream or grab the dentist's hands and instruments.

Sometimes, children also have physical limitations that make dental treatment more difficult. Some children cannot open their mouth wide enough or hold it open long enough. Uncontrollable movements can also interfere with dental treatment.

A portion of this article has been adapted with permission from materials originally published by Johnson & Johnson Dental Care Company.

The Papoose Board is a restraining device that provides stabilization and protection to the patient. This device limits movements that the child may be unable to control and allows the dental professional to work safely and efficiently.

Dentists commonly use several techniques, sometimes called behavior management techniques, to gain the cooperation of child patients, to control disruptive behavior or to prevent patients from causing injury to themselves due to uncontrollable movements. The dentist should discuss this subject with parents before treatment begins. The following recognized techniques may be used individually or in combination depending on the child's needs:

Tell-Show-Do: Children have less anxiety when they know what to expect. With this technique, the dentist uses simple words to tell the child what is to be done. Then, the dentist uses a model to demonstrate the procedure. After "telling" and "showing," the dentist performs the procedure. The child is praised when he cooperates.

Positive reinforcement: This technique rewards the child who displays *any* desirable behavior. Rewards may include praise, compliments, a pat on the back, a gentle hug or a prize.

Voice control: When a child exhibits disruptive behavior, the dentist regains his or her attention by using an abrupt change in tone or volume of voice. What the dentist says is less

- Improves coordination, postural control and muscle tone.
- Provides independence.
- Secured in center with belt or seat.
- Trade-in policy.
- S,M,L
- Covered by most insurance companies.

THE WATER WALKER

- Prone or supine support.
- Contour lines that allow use of arms and legs.
- Straps to secure person on float.
- Pillow for head support.
- S,M,L

AQUATIC THERAPY FLOAT

Contact:
AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

Circle # 170

Hey Mom, Now There's A Break From the Weather

The WEATHERBREAKER™
A COLLAPSIBLE CANOPY FOR WHEELCHAIRS/SCOOTERS

- Protects your child from the rain
- Shades your child from the sun
- Fits all wheelchairs
- Mount it once, then put it on or take it off in a snap

Call your local dealer today!
or order direct
800-795-2392

The WEATHERBREAKER™ Base Model $115.00

When Ordering Include:
1. Manufacturer and model of Wheel Chair/Scooter
2. Choice of teal green, navy blue, cranberry red or charcoal gray
3. Side windows add $20.00, Rear window add $10.00

Checks – Money Orders – Credit Cards Accepted
DIESTCO Manufacturing • P.O. Box 6504 • Chico, CA 95927
Quality Guaranteed • Made in the USA

Circle # 262

important than the sudden nature of the voice change.

Hand-over mouth exercise: The dentist tells a child who is screaming that he is going to place his hand over the child's mouth. When the dentist has placed his hand over the child's mouth, he speaks directly into the child's ear and tells the child that if the noise stops, he will remove his hand. When the child stops screaming, the dentist removes his hand from the child's mouth and the child is praised for cooperating. If the child begins screaming again, the exercise is repeated. At no time is the child's airway restricted. It is important to emphasize that this technique is never used as a punishment, but as a means of gaining the child's attention and encouraging cooperation.

Mouth prop: This is a device that is placed in the child's mouth to prevent involuntary mouth movements or accidental closing. This prevents injury and allows jaw muscles to relax for ease of swallowing so the dental professional can complete the procedures safely and efficiently.

Physical restraint by dentist or assistants: Dental staff restrain the child from undesirable movement by holding down his hands or upper body, stabilizing his head and/or controlling his leg movements.

Papoose Board: This is the most common of several safety devices used to limit disruptive movement. The Papoose Board prevents injury and enables the dentist to safely provide the necessary treatment.

Hospital Dentistry

For some children with medical complications or in rare instances where conscious sedations are ineffective, a child's dental treatment may be accomplished in a hospital operating room under general anesthesia. But because general anesthesia may be considered a risky procedure itself, its use should be considered only as a last resort. Often, a combination of behavior management techniques can be an alternative to general anesthesia.

Other Resources

If you need additional information or help in locating a dentist who works with children who have disabilities, several groups may help you:

Academy of Dentistry for Persons with Disabilities
211 East Chicago Ave.
Chicago, IL 60611
(312) 440-2660

American Academy of Pediatric Dentistry
211 East Chicago Ave.
Chicago, IL 60611
(312) 337-2169

American Dental Association
211 East Chicago Blvd
Chicago, IL 60611
(312) 440-2500

American Dental Hygienists' Association
444 N. Michigan Ave, Ste 3400
Chicago, IL 60611
(800) 243-2342

Attends

Quality Incontinent Care Products

Help keep skin dry and provide outstanding leakage protection!

Protection For All Your Needs from

ARC Home Health Products

- Full line of products in stock
- UPS deliveries to your door
- No add-on shipping & handling charges
- Personal, knowledgable service
- VISA/Mastercard accepted

Ultra Attends Briefs

Your satisfaction is our concern! Call Us!

1-800-278-8595 for more information

Attends Washcloths

ARC Home Health Products
RR#4 Box 161 • Oneonta, New York 13820

An Affirmative Enterprise, providing jobs for people with disabilities.

Attends Briefs
Available In Youth

SAVE! BUY BULK

Attends Insert Pads

Circle # 229

Bricks, Sticks, & Crayons??

Child Care facilities have become a necessity for businesses of all kinds. Women today consitute over 50 percent of the nation's workforce, making on-site day care a facility every corporation, municipality, university or hospital needs.

GSGSB/H, a Hillier Group Company, is a fully comprehensive architectural, engineering and planning firm that provides all the professional services for the design of successful child care facilities.

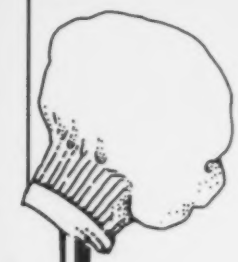
- Special designs for disabilities
- Innovative constuction technology
- State-of-the-art, expandable designs
- Customized landscaping & playground design
- Safe, affordable and durable

GSGSB/H

A Hillier Group Company
1212 South Abington Road
Clarks Summit, PA 18411
717/586-4000

The Hillier Group

Circle # 264



Any Occasion
• • • • •
Holiday Favorites
• • • • •
Business Luncheons
• • • • •
Specialty Chocolates
• • • • •
Birthday Parties
• • • • •
Special Party Box

JENNIFER'S *Catering*

Call Jen at (201) 489-0871
Northern New Jersey area only

Circle # 246

One size does not fit all!

Children's Specialized Hospital is dedicated exclusively to serving the special needs of children and adolescents.

- Child Study Team
- Learning Disabilities
- Attention Deficit Disorder
- Early Intervention / Pre-School
- Speech and Hearing
- Psychological Services
- Rehab Technology
- Occupational Therapy
- Physical Therapy
- Cognitive Remediation
- Day Hospital
- Recreational Therapy
- Augmentative Communication/ Computer Evaluation
- Nutritional Counseling

Children's Specialized Hospital

MOUNTAINSIDE • FANWOOD • TOMS RIVER
For information in North Jersey call **(908) 233-3720** Ext. **8429** or **8439**
For information in Central and South Jersey call **(908) 914-1100** Ext. **706**

Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation" — the highest distinction awarded by the Joint Commission on Accreditation of Healthcare Organizations.

Circle # 185

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent.*

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
244	Academic Therapy	54
9	AccessAble Environments	74
	Apple Computer	12
170	Aquatic Therapy	64
229	ARC/Otsego	65
2	AT&T	C2
217	Barrier Free Lifts	34
6	Berkshire Meadows	62
7	JA Preston	C4
115	Braun Corporation	C3
267	Chairscholars Foundation	76
185	Children's Specialized Hospital	66
90	Chrysler Corporation	27
186	Civitan International	25
227	Clinician's View	79
13	Columbia Medical	41
11	Columbia Medical	28
109	Consumer Care	48
18	Cumberland Hospital	58
243	Danmar Products	7
19	Devereux Foundation	39
262	Diestco Manufacturing	64
20	Duraline Medical Products	71
300	EP Library	82, 83
25	Equipment Shop	30
26	Estate Planning	30
27	Evergreen Center	60
261	Finn Strong Designs	29
29	Flaghouse	7
31	Freedom Designs	3
265	GTE	12
36	Haverich Ortho Sport	39
38	Heartspring	75
264	Hillier Group, The	65
39	HMS School	60
40	Homecare Products	19
42	Innovative Products	56
211	InvoTek	50
246	Jennifer's Catering	66
46	KID-KART/KID CARE	9
147	Kimberly Clark	11
191	Kotton & Koala	75
47	Kuschall of America	5
48	Laureate Learning	34
268	Meeting Street Center	47
168	Merrill Lynch	21
169	Milani Foods	51
1	NR Labs	30
219	Oralgiene	63
263	Pediatric Projects	54
177	Racing Strollers	56
103	Rhamdec	13
65	Ricon Corporation	35
44	Rifton	49
232	Rock N' Roll	22
68	Sentient Systems Technology	49
269	Sigma Tau	31, 32
202	Temasek Telephone	38
122	TMI	57
194	Toys for Special Children	81
266	Treadle Power	13
82	Triaid	74
188	Whitmyer Biomechanix	38
162	Willow River Farms	72
86	Woodbury Products	25

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $ 50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

770

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date: October 31, 1994

Expiration Date: January 31, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000
2❑ $30,001 - $40,000
3❑ $40,001 - $50,000
4❑ $50,001 - $75,000
5❑ $75,001 - $100,000
6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent
10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months
17❑ three months 19❑ one year

Issue Date: October 31, 1994

Expiration Date: January 31, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFILED MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

Market Place

Bibs

Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

Bulletin Board

LINCS-BBS C/O PHP
535 Race Street, #140
San Jose, CA 95126
(408) 294-6933 BBS
(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and prof. caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-8-1, up to 14,400 baud, 24 hours.

Child Care

Working Solutions
51 E. 42nd Street, Ste. 1511
New York, NY 10017
(212) 922-9562
Agency that specializes in placing professional nannies to work with children who have special needs. NY, NJ & CT

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical
SAVE $250 on Tri-Stander or Chameleon. Equipment and supplies discounted to 50%. Call 800-877-9100 for free brochure.

To place an ad, contact Barbara Nastro at (201) 680-4874

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

Maryland

Choice Seating & Rehab
501 North Centre Street
Cumberland, MD 21502
(800) 327-8713 / (301) 722-6300
Serving Western MD, SW PA, and adjacent WVA. Custom W/C, home & van lifts, electric scooters, PT & OT on staff. Sales and service.

New Jersey

Health Science, Inc.
418 Wall Street, Princeton, NJ 08540
(609) 924-7616 & (800) 841-8923
Authorized Dealer for:
Ablenet • Abovo • Ability Research • Cannon • Franklin • Innocomp • IntelliTools • Mayer-Johnson • MultiVoice by IAT • Tash • Tiger • Toys for Special Children
Take advantage of our loaner, leasing and discount program.

New York

Dowd Medical
1010 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been serving the area since 1930. For personal service and quality equipment call Dowd.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Summers Laboratories, Inc.
Collegeville, PA 19426
(800) 533-SKIN (7546)
Triple Paste™ for diaper rash and chronic irritation. Used at leading children's hospitals. Available without prescription. Call now for free treatment information.

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Put Your Honey in a Gunny

The *GUNNY SACK™*
Lap, Leg and Feet Cover
- Fleece lined for warmth
- 100% waterproof

To Order Call
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

Software

UCLA Microcomputer Project
1000 Veteran Avenue/Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
Catalog of dev. appropriate software for children w/disab. 18 mths-5 yrs. Apple, Mac, IBM, cause/effect, game format, basic preschool concepts

Toys & Hobbies

Antoni Toys and Products
1-800-826-8664
One-piece underwear up to 80 lbs, hand-made "Reality Dolls", books on computer disk, educational books, colorful toys, spoons & cups, diapers, balls, video tapes and more! Call for a free catalog.

TFH (USA) LTD.
4449 Gibsonia Road
Gibsonia, PA 15044
(412) 444-6400
FREE CATALOG! Fun and achievement products for children with special needs. Call or write for more information

BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

Audiotapes

"Little Bits of Rainbow"
12 original songs in the Judy Collins tradition, for parents of children with special needs. By Marianne Kallen. Cassette only, $11.95, P.O. Box 1393, Highland Park, IL 60035

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourrette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

VAN CONVERSION DEALERS

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

ABDC is your link to parent partners

ASSOCIATION OF BIRTH DEFECT CHILDREN • ASSOCIATION OF BIRTH DEFECT CHILDREN •

The Association of Birth Defect Children (ABDC) is your link to parent partners, birth defect information, newsletters, fact sheets, and support referrals. Link with families of children with similar disabilities through ABDC's National Birth Defect Registry.

To receive a free parent matching registry packet and information about ABDC's other projects and services call: 1-800-313-ABDC (24 hours a day)

☑ **0853 During the Combined Federal Campaign in your workplace.**

Circle # 218

IT'S MORE THAN JUST A STROLLER

It's Discovering Together

It's Sharing the Experience

STROLLER Pack SPECIAL NEEDS

It's Finding Access to the World!

Adaptive Positioning Hardware
Backpack, Extending Handle, Climbs Steps
Quick Release Axles, Folds Flat

1-800-487-9652

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

West Virginia

Tri-State Mobility Equipment Co.
940 Cleveland Avenue SW
Canton, OH 44707
1-800-343-3150
and
2735 Dorr Street (rear)
Toledo, Ohio 43607
1-800-345-3150
New-Used-Trade-Buy full size/mini-van modifications, 129 years employees service to the disabled community. Trade-ins welcomed, financing available, NMEDA member

Remember to tell them you saw their ad in EXCEPTIONAL PARENT!

continued from page 9

with having two children who have the same chronological age but different developmental ages. We are also interested in finding out the types of strollers or other transportation devices parents used to get out with their children.

How do other mothers of multiples with special needs get support? Have any of you, for example, joined a mothers of twins club? If so, what was your experience with it? I feel blessed to have connected with a few mothers in similar situations, but overall, I feel there is a tremendous lack of information on this subject in much of the literature and resources on raising twins. Mothers of twins, let's unite!

D.C., California

Self-Catheterization

My friend's 10-year-old daughter has spina bifida and receives orthopedic services through a fine hospital that is known for providing services to children with spina bifida. However, staff members at this hospital seem to be at a loss when it comes to teaching this young girl how to catheterize herself. This is a tremendous frustration to the family because it prevents their daughter from enjoying spontaneous activities with friends or other family members. It is impossible to plan all activities around the function of one's bladder, nor do all activities take place in a clean, clinical setting. Surely, other young women with spina bifida have had to jump this hurdle towards independence. Can anyone offer some help?

D.R., Oregon

Buying a Used Van

I am the parent of a young man who uses a wheelchair for mobility. He is deaf, blind and has physical disabilities. I am interested in purchasing a used Plymouth Voyager or Dodge Caravan mini-van that has been converted with a hydraulic lift or ramp.

I'd love to get some ideas on how to locate a used vehicle of this type. I would also like information and opinions about the various hydraulic lift systems and ramps that are available; I don't want to make an expensive mistake!

W.M., New York

Russell-Silver Syndrome

I am the parent of a five-year-old girl with Russell-Silver syndrome. I would like to hear from parents of children with the same diagnosis to compare notes. I have a lot of questions, and most of the doctors we've seen can't tell us much.

Meagan is basically a healthy child. She grows steadily, but remains below the fifth percentile for her age; one side of her body grows at a slower rate than the other. She also has a severe delay in speech development.

My main concern is to make sure she gets an appropriate education. Russell-Silver syndrome is rare, and I'd appreciate any information I can get.

W.W., Illinois

EDITOR'S NOTE: Contact the Association for Children with Russell-Silver Syndrome, 22 Hoyt St., Madison, NJ 07940, (201) 377-4531. They can provide you with more information about the syndrome and can put you in touch with other families.

STATEMENT OF OWNERSHIP MANAGEMENT AND CIRCULATION

Published annually as required by the U. S. Postal Service

EXCEPTIONAL PARENT, Date: October 1994. Frequency of issue: 12 Times per year. January through December. Number of issues published per year 12. Annual subscription price: $24, individual; $24 organizations, schools and libraries. Location: 209 Harvard Street, Suite 303. Brookline, MA 02146 - 5005. Publishers address: Psy - Ed Corporation, 209 Harvard Street, Brookline, MA 02146. President and Publisher: Joseph M. Valenzano, 6 Pickwick Lane, Woodcliff Lake, NJ 07675. Editor in Chief: Stanley D. Klein, Ph.D., 82 Evans Rd., Brookline MA 02146. Stockholders holding 1% or more of the total amount of stock: Stanley D. Klein, 82 Evans Rd., Brookline, MA 02146; Thomas H Lee, 75 State Street, Boston, MA 02109; Joseph M. Valenzano, 6 Pickwick Lane, Woodcliff Lake, NJ 07675; Bernard E. Koff, c/o Pro Data Communications, 449 Mt. Pleasant Ave., West Orange, NJ 07052; Stephen N. Gerson M.D., Revocable Trust, c/o Steven N. Gerson M.D., 12 Clematis, Lexington, MA 02173; Corey Kupersmith, Clinical Communications, Greenwich Office Park #6, Greenwich, CT 06830; Herbert Whitaker, 6500 Prairie Dune, NE, Albuquerque, NM 87111; Fred Ballerino, 2400 Feather Sound Dr., Apt. 214, Clearwater, FL 34622; Susan Klein, 1217 East University, Bloomington, IN 47401; Leonard LaFebre, 327 Solano, NE, Albuquerque, NM 87106; Lawrence Qualiano, 59 B South Maple Ave., Park Ridge, NJ 07656; The Bell Family Trust, c/o Steven Bell, 865 Muskingham, Pacific Palisades, CA, 90272; Allen M. Landers, 1385 York Avenue - 26F, New York, NY 10021; Jane Carlisle Spivey, 20 Brookside Dr., Apt. 3J, Greenwich, CT 06830; Kenneth R. Rossano, C/O Cassidy and Associates, 75 State Street, Suite 2200, Boston, MA 02109; Dorothy Carver, Box 577, Barnstable, MA 02630; Robert K Hopkins Jr., 25 Hillcrest Road, Mountain Lakes, NJ 07046; Harold Turner, 19195 Mystic Point Drive, Apt. 106, Aventura, FL 33180; Todd M Abbrecht, 1 Raymond Street Unit F, Allston, MA 02134; Judith Parmet, 141 Harbor Road, Harbour Acres, Port Washington, NY 10050; Gilbert W Chapman Jr., 121 Factory Pond Road, Locust Valley, NY 11560; Terri Sutera, 223 South Maple Ave., Park Ridge, NJ 07656; Kerry Cannon, 411 East 53rd. St., Apt. 4H, New York, NY 10022; Barbara Nastro, 494 Essex Ave., Bloomfield, NJ 07003. There are no known bondholders owning or holding 1% or more of total amount of bonds, mortgages or other securities.

EXTENT AND NATURE OF CIRCULATION

Avg. no. issue preceding 12 months		Actual single issue nearest filing date
53540	Total # of Copies Printed	58547
37024	Paid Circ: Mail Subs	40050
37024	Total Paid Circulation	40050
15500	Free Distribution	17500
52524	Total Distribution	57550
1016	Office Use, Leftovers	997
53540	TOTAL	58547

I certify that the statements made by me above are correct and complete. —Stanley D. Klein, Editor in Chief

Bladder and Bowel Control Problems?

DURALINE MEDICAL PRODUCTS

Can Help You With *Discreet Home Service!*

- Trained, knowledgeable consultants
- Individual personalized attention
- Hard to find YOUTH sizes
- Disposable and reusable products
- Automatic shipments available
- Fast direct-to-your-door delivery

Call Today For A FREE Catalog!

1-800-654-3376

DMP DURALINE®

324 Werner St. • P.O. Box 67 • Leipsic, OH 45856

Circle # 20

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: **CRI**
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle # 162

Annandale Village

Private, 501(c)(3)
Nonprofit Community

"THEIR COMMUNITY...WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.

- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.

- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae,
Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710

Camp Huntington
33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS
A co-ed residential camp for the:

- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

"MAXIMIZING INDIVIDUAL POTENTIAL"
Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.

- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

Special Force Family Ministries

A PLACE TO CALL HOME
Special Force Family Ministries operates superior quality residential programs for adults with mental retardation in private homes near Minneapolis, MN and Springfield, MO. Residents become members of individual families where Christian values are affirmed. Community involvement. Recreational opportunities. Affordable rates. Established 1973. Call for details.

Contact:
Special Force Family Ministries
P.O. Box 47, Waconia, MN 55387
(612) 442-4441

TO PLACE AN AD
in the Schools, Colleges, & Residences Directory, contact Barbara Nastro
(201) 680-4874
(201) 680-8355 fax

WHAT'S HAPPENING

SUPPORT GROUPS

• Pen-Parents is a free support network for parents who have experienced pregnancy loss or the death of a child. Members receive a list of parents who have experienced similar losses and contact lists for single or divorced parents, adoptive families and sterile or infertile parents. Grandparents are invited to join Pen-Grandparents.

Pen-Parents publishes *Optional*, a quarterly newsletter. Annual subscription is $12. *PAILS of Hope*, a bimonthly newsletter for parents going through subsequent pregnancy, is $10 a year. Contact Pen-Parents, P.O. Box 8738, Reno, NV 89507-8738, (702) 826-7332.

• ***Schwachman syndrome*** is a digestive and respiratory disorder that can result in short stature, problems with bone growth, chronic diarrhea and persistent respiratory and skin infections. A new support group is forming for parents who have children with this syndrome. Contact Joan M. Mowery, 44 Meadowlark Rd., Vernon, CT 06066, (203) 870-5454.

Follow the Fairy Tale Trail

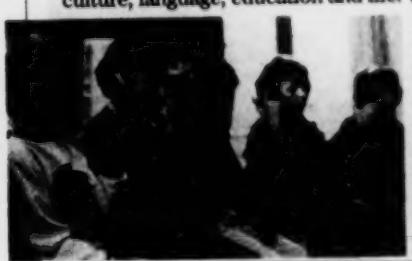
The Fairy Tale Trail is a Halloween house that is accessible and fun for all children. Started five years ago by Lekotek, a resource center for families with children who have special needs, Fairy Tale houses are springing up all over the country.

Visitors to one of these houses follow a "fairy tale trail" through eight storybook-theme rooms, interacting with costumed characters, trick-or-treating and enjoying sensory-stimulating and accessible activities. "At the Fairy Tale Trail, children with and without disabilities can share in the fun of the holiday together—side by side," said Judy Hynes of the Auxiliary Foundation of the Woman's Club of Evanston, Illinois, co-chairman of this year's Evanston event.

Lekotek and the Auxiliary Foundation offer a 50-page guide on how to build the house in other communities. The guide costs $15. Contact Lekotek, 2100 Ridge Ave., Evanston, IL 60201, (800) 366-7529.

In The Land of The Deaf

In The Land of The Deaf is an award-winning French documentary about deaf culture, language, education and life. The film has English subtitles, but most of the subtitled dialog is never spoken—rather, filmmaker Nicolas Philibert allows deaf children and adults to tell their own stories, most often using French Sign Language. The film earned "two thumbs up" from reviewers Siskel and Ebert who called it "a wonderful documentary that will take you into the deaf world in a way that you have never seen or heard before."



In The Land of The Deaf made its U.S. theatrical premiere during National Deaf Awareness Week in September. As *Exceptional Parent* went to press, the film was scheduled to be shown in the following U.S. cities:

Boston, MA: Museum of Fine Arts ..... weekends thru Nov.
Austin, TX: Texase Union Films ..... Nov. 4–10
DeKalb, IL: Egyptian Theater ..... Nov. 11–12
Minneapolis, MN: Walker Art Center ..... Nov. 25 & 30
Minneapolis, MN: University Film Society ..... Dec. 2–5
Brookline, MA: Coolidge Corner ..... Dec. 2–8
Los Angeles, CA: Landmark NuArt ..... Dec. 8–14
Philadelphia, PA: TBA ..... Jan. 1995

As additional engagements are added to this schedule, the film's U.S. distributors will inform interested people of upcoming showings in their local areas. To be added to this mailing list, send your name and address to: International Film Circuit, P.O. Box 1151, Old Chelsea Station, New York, NY 10011.

VACC Camp 1995

The Miami Children's Hospital hosts a free, week-long overnight camp each spring for ventilation-assisted children (children who need oxygen, trachs, ventilators and/or CPAP) and their families. VACC Camp '95—the tenth anniversary session—will be held April 1-7, 1995. Application deadline is January 6. The program includes swimming, field trips, campsite entertainment, structured games and more. An around-the-clock medical staff is available. For more information, contact Cathy Klein, VACC Program Coordinator, Ventilation Assisted Children's Center, Division of Pediatric Pulmonology, Miami Children's Hospital, 3200 S.W. 60 Court, Suite 203, Miami, Fla. 33155-4076, (305) 662-8222.

Video Lending Program

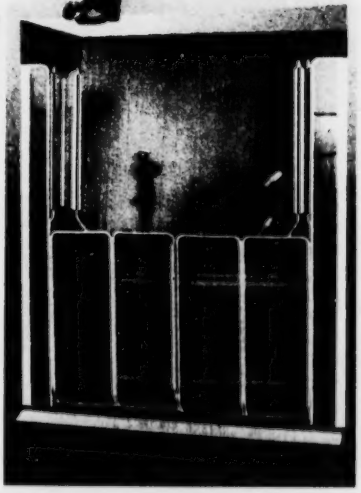
A free video-lending program offers more than 150 informational videos on disability-related subjects to individuals with disabilities and their families. Videos deal with a variety of subjects including assistive devices, home modification, computer accessibility, family life, employment, health concerns, travel and wheelchair skills. Further information is available from SCI Video Access, Spinal Injury Network International (SCINI), 3911 Princeton Dr., Santa Rosa, CA 95405-7013, (800) 548-2673.

777

AccessAble. Means bath time is child's play.

Accesshower, barrier-free bathtub replacement. An easy-to-do 1-day, no-plumber project! Safe investment—goes with you if you move.

Safe, wet shower or bath fun. Goes to the beach or pool, too.
AdjustEase Washchair: your sensible back- and back-saver!



Safe. Comfortable. Fun. Easy to install. Economical.

AdjustEase. *One-hand adjustable washchair. Widest size and height range anywhere. Durable, rustproof. Many other features and options.*

CareFree Accesshower. *Exclusive split door. Open top half while the watertight bottom stays closed. Both of you are safe. You're dry!*

FIND OUT ABOUT OUR 350+ BATH ACCESS PRODUCTS FOR EVERY BODY.

AccessAble
ENVIRONMENTS + PRODUCTS
1 800 285 2525

YES, WE CAN FILL 3RD PARTY PURCHASES THROUGH LOCAL DEALERS! JUST CALL US FIRST!

Circle # 9

Every Child's Dream – A Bike on Christmas Morning!

TRIAID
REHABILITATION PRODUCTS
P.O. Box 1364 • Cumberland, MD 21502
301-759-3525
1-800-306-6777
VISA-MasterCard

ORDER NOW FOR CHRISTMAS DELIVERY!

Copyright TRIAID 1990. All specifications are subject to alteration without notice.

Circle # 82

Publications

• *The Maap* is a quarterly newsletter for families of "more advanced autistic people." Features include letters, interviews with doctors, information about resources and calls for research participants. Annual subscriptions are $8 ($11 outside the U.S.). *The Maap*, P.O. Box 524, Crown Point, IN 46307.

• Stuttering affects 2.5 million American children and adults. Although stuttering typically begins between the ages of two and seven, it sometimes appears for the first time in a school-age child or adult. *Is It Stuttering?* is a publication that helps parents determine if their child is beginning to stutter or is experiencing only a temporary disfluency. *I Think My Child is Stuttering. What Should I do?* is another publication that provides practical tips to help parents respond to children with disfluent speech. Both publications are free and available by contacting the American Speech-Language Hearing Association (ASHA), 10801 Rockville Pike, Rockville, MD 20852,(800) 638-8255.

The Stuttering Foundation of America offers free copies of *The Child Who Stutters at School: Notes to the Teacher.* Contact the Stuttering Foundation of America, P.O. Box 11749, Memphis, TN 38111-0749, (800) 992-9392.

• *Little Bones Newsletter* is a new quarterly newsletter by, for and about teenagers with osteogenesis imperfecta (OI). Features include guest medical columnists, advice on nutrition, fashion tips and a column for siblings. Annual subscriptions cost $5. *Little Bones Newsletter*, 1725 Lakeview Ave., South Milwaukee, WI 53172.

• The Lighthouse offers *EnVisions*, a newsletter for parents and professionals involved with children with visual impairments. The free newsletter is published three times a year.

The Lighthouse also offers *Technology for Tots*, an $8 booklet introducing parents and teachers to computer technology for children with visual impairments. The Lighthouse, 111 E. 59th St., New York, NY 10022, (800) 334-5497.

• Interested families can request a free sample issue of *Adoptive Families*, a new magazine from Adoptive Families of America that replaces the group's 27-year-old *OURS: The Magazine of Adoptive Families.* The magazine plans to

778

cover issues regarding the adoption of children with disabilities. *Adoptive Families*, 3333 Highway 100 North, Minneapolis, MN 55422, (800) 372-3300.
• The National Association for Parents of the Visually Impaired (NAPVI) sells several books that may also be of interest to parents of children with disabilities other than visual impairment. *How to Pack 'Em In: A Guide to Planning Workshops* is full of handy tips for staging a meeting, from the very first idea to the end result—a successful workshop ($5). The *Legislative Handbook for Parents* is written by parents to help other parents get involved with the legislative process on the local, state and national levels ($7).

Your Child's Information Journal provides parents with a format for maintaining careful records of important information about a child's development and medical/educational histories. Journal pages fit in a three-ring binder ($7.50).

For 1–3 books, add $2 for shipping. For 4 or more books, add $5. NAPVI, P.O. Box 317, Watertown, MA 02272, (800) 562-6265.

Bundle Hug'r™

... helps keep an exceptional child's legs in place and warm by completely wrapping them comfortably. Two styles available.

Fully assembled in the United States with U. S. materials. Quality workmanship. Carefully inspected.

Kotton Koala ... more than a hug!

P.O. Box 178 • Fort Jones, CA 96032

(916) 468-5475 FAX: (916) 468-5492

Circle # 191

We focus on going home

...because that's where the heart is.

Home is where the heart is, but sometimes children with multiple disabilities need special help beyond their parents and school districts. Financing multi-year private school placements can be costly too. But now a school known for its successful individualized education programs is offering an extended assessment and treatment program. That school is Heartspring.

Curt came to Heartspring not because he needed a long-term, intensive program, but because his skills had plateaued, and problematic behaviors were unmanageable. He needed a program with a fresh perspective. With Heartspring's team approach, Curt has the resources he needs: specialists in the areas of special education, audiology, physical, occupational, and speech/language therapies, pediatric development medicine, psychology, and behavior management. Together, they will address his complex needs in a comprehensive, interdisciplinary program designed to continue after he returns to his home environment.

Just think! Curt enrolled this spring, and he'll be going home before school starts this fall. When he does, a Heartspring staff member will return home with him and stay a few days to make reintegration as smooth and effective as possible.

Home is where the heart is, and Heartspring is where the hope is. Let us build a program for your child. Call today.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800- 835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

continued from page 13

to repeat instructions or modify assignments at times, it would have made things much more difficult.

At first, it was very hard to see Laura struggle with OCD. With her learning and hearing problems, it seemed like she already had enough to cope with, but it has been very encouraging to see the progress that she has made. You really do cheer for the small victories!

M.S., Indiana

☐ My eight-year-old daughter was diagnosed with OCD in March 1993. She also takes medication daily. She has made nice progress and we are very pleased.

You might want to get in touch with the OCD Foundation, P.O. Box 70, Milford, CT 06460. They have a newsletter for parents, and a special newsletter for children.

K.S., New York

Adoptive Parents

M.W. (August 1994) is the adoptive mother of a three-year-old girl who has multiple disabilities—including cerebral palsy, developmental delays and a visual impairment—caused by "shaken baby syndrome" when she was seven months old. Because her daughter has multiple disabilities, M.W. has been unable to find appropriate support groups. She wanted to correspond with other adoptive parents of similar children.

My husband and I also have adopted a daughter who has cerebral palsy. She was born very prematurely—at 24 weeks gestation. She has developmental delays and a visual impairment. She is bright and cheerful.

I also have had trouble with support groups—adoption support groups cater to parents of "normal" kids, but members of support groups for parents of children with disabilities seem to lose interest in us when they find out that Chelsea is adopted. I remember being at a meeting where some mothers were talking about their problems with Medicaid. One mother asked me what kind of insurance Chelsea had. After I said "adoption Medicaid," I could feel that they were looking at me differently. It seems they don't see me as a "real mom."

M.W., Georgia

Gift Subscriptions

As we approach the holiday season, we suggest that readers purchase gift subscriptions for other parents, grandparents, caring therapists, educators and libraries. Also consider a gift subscription for your favorite clergy-person in time for the December issue on religious education.

SCHOLARSHIPS AVAILABLE

Up to five college scholarships are being offered for the fall of 1995 for a four-year period. Each scholarship provides $3,000 per year ($12,000 total) to each student. Only current high school seniors and college freshmen will be considered.

Applicants should be physically challenged, in a wheelchair, and could not attend college without this help.

All young men and women will be considered without regard to race, color, creed, or state of residence. A private interview is **not** required.

We require a 500-word "statement of need" explaining your physical condition, educational background, and financial status. For scholarship application, write to:

"Doc" and Alicia Keim, Chairscholars
Silver Dollar Ranch, No. 38
Odessa, FL 33556
(813) 920-2737

Deadline Jan. 15, 1995

Chairscholars

"Helping physically challenged students in chairs go to college."

Circle # 267

780

Networking

Information from The National Parent Network on Disabilities

NPND Holds First National Conference Call

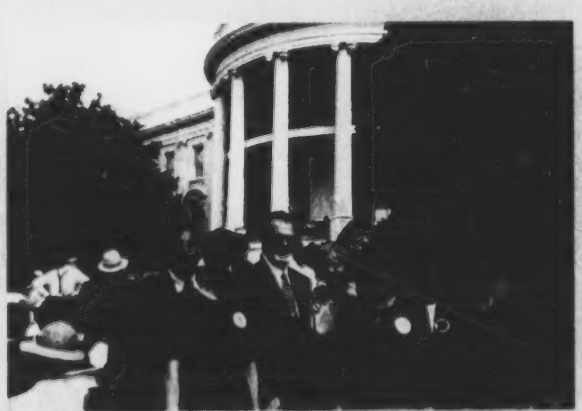
More than 75 people from 17 Parent Training and Information Centers and other organizations participated in NPND's first national teleconference held on August 24, 1994.

The 90-minute teleconference, broadcast from NPND's national office in Alexandria, Virginia, focused on the detrimental effects of legislative amendments to the Improving America's Schools Act of 1994 (IASA)—previously known as the Elementary and Secondary Education Act—and the Individuals with Disabilities Education Act (IDEA).

A panel provided an analysis of amendments dealing with violence and weapons in school, regulations of the Perkins Vocational Education Act and nullification provisions of IASA. Panelists included Patricia McGill Smith, NPND's executive director; Lucy Watkins of the Center for Law and Education and Larry Searcy of NPND. Paul Marchand, director of governmental affairs of the Arc, joined the panel from his Washington, D.C. office.

NPND plans to hold future teleconferences.

NPND members and friends gathered at the White House July 27 for a celebration of the fourth anniversary of the Americans with Disabilities Act with President Bill Clinton, Hillary Clinton, Vice President Al Gore and Tipper Gore. [From left to right] Connie Hawkins of New Jersey; Patricia Smith, NPND executive director; Janet Myers of Texas; Joanne Butts of Washington; Judith Raskin of New Hampshire; Terri Dawson of Wyoming and Debra Johnson of Idaho.



[From left to right] Joseph M. Valenzano, Jr. and Kim Schive of EXCEPTIONAL PARENT; Tom DeLuca of Toys "R" Us; Nona Wells of Boston; Patricia Smith, NPND executive director; Jeanne McIntosh of Toys "R" Us; Pam Steneberg of California and Martha Ziegler of Boston.

NPND Establishes Electronic Bulletin Board

On September 6, NPND started its own electronic bulletin board on SpecialNet. Known as NPND.update, the board features up-to-the-minute summaries of federal legislative activities from a parent-and-family perspective as well as information regarding other NPND activities. The board can be found under NPND.update in the SpecialNet opening menu. Because the NPND bulletin board is a read-only board, comments about information on the board can be sent through e-mail to NPND.DC.

NPND Holds Congressional Briefing

As *Exceptional Parent* was going to press, NPND was planning to hold its first parent briefing for members of Congress and their staff. The briefing was planned for October 3, at the Rayburn House Office Building to discuss the reauthorization of IDEA. After the briefing, which is being sponsored by Rep. Major Owens, D-NY, NPND members were planning to meet with their local legislators to discuss the needs of children with disabilities.

Join NPND today!

781

NPND Honorees

As *Exceptional Parent* was going to press, NPND was planning to honor four people at its annual meeting on October 1:

• **Carol Rasco** is the chief domestic policy advisor to President Clinton. For more than 20 years, Rasco, the mother of a son with disabilities, has provided leadership through her first-hand experiences, volunteer activities and professional life to gain services for children with disabilities. In her current position, Rasco has led the fight for the Family Leave Act and universal health care coverage, among other things.

• **Justin Dart** was a national leader in gaining passage of the Americans with Disabilities Act. In addition to serving as chairperson of the President's Committee on the Employment of People with Disabilities and the federal Commissioner of Rehabilitative Services, Dart is a constant source of motivation and inspiration for the disability advocacy community.

• **Pam Steneberg** has provided leadership on the national level and in her home state of California. As the parent project coordinator of the Disability Rights and Education Fund (DREDF), Steneberg has provided assistance to countless parents and parent organizations throughout California. For several years, Steneberg has led the fight for people with disabilities as secretary of NPND's board of directors and as chairperson of the NPND Legislative Committee.

• **Charles Lazarus**, chief executive officer of Toys "R" Us, has provided national leadership to the corporate world through his efforts to test and market toys specifically to families of children with disabilities. In conjunction with NPND, Toys "R" Us published and distributed 700,000 copies of the *Toy Guide for Differently-Abled Children*. The guide, the first of its kind, has had a tremendously positive impact on children with disabilities and their families.

NPND's annual meeting reception was being sponsored by the National Association for Medical Equipment Services.

Parent Training and Information Center News

The Parent Network Center in Buffalo, New York has received a state grant to train parents throughout the state to provide support, information and other services to parents. The center has also received expanded federal funding to continue its services. Congratulations to **Joan Watkins**, the center's executive director, and her crew for all their good work.

NPND invites you to join

Mission: The National Parent Network on Disabilities (NPND) was established to provide a presence and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents and resources to influence and affect policy issues concerning the needs of people with disabilities and their families.

☒ I/we would like to join the NPND.

NAME: _____

ORGANIZATION: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

HOME NUMBER (____)_____ WORK NUMBER (____)_____

DO YOU WANT TO BE ON THE NPND FAX TREE? (____)_____
(your fax number)

Please return this form with your check made payable to: NPND, 1600 Prince St., Suite 115, Alexandria, VA 22314, (703) 684-6763, FAX: (703) 836-1232

Membership fees

Parent Coalition —*Voting* (Call NPND for details)	$Sliding Scale
Affiliated organization	100
Parent group	50
Parent/Individual with a disability (Stipend available)	25
Professionals	40
Contributor	1000
Corporation	1000
Sustaining	3000

The National Parent Network on Disabilities Board of Directors

Richard Burden
IN*SOURCE, South Bend, IN

Joanne Butts
Washington PAVE, Tacoma, WA, *Vice President*

Amparo Crespo DeCastro
Asociacion de Padres Por Bienestar de Niños, Impedidos de PR, Inc., Rio Piedras, PR

Connie Curtin
Vermont Parent Information Center, Winooski, VT

Diana Cuthbertson
Statewide Parent Advocacy Network (SPAN), Westfield, NJ, *President*

Kathryn Erickson
Pathfinder Services of North Dakota, Minot, ND

Joe Garcia
Touchstones, Seattle, WA

Paula Goldberg
PACER Center, Minneapolis, MN

Sweet Alice Harris
Parents of Watts, Los Angeles CA

Connie Hawkins
Exceptional Children's Assistance Center (ECAC), Davidson, NC, *Past President*

Bonnie Johnson
Arkansas Parent Support and Information Network, Little Rock, AR

Joan Kilburn
MATRIX, A Parent Network & Resource Center, San Rafael, CA, *Treasurer*

Sue Pratt
CAUSE, Lansing, MI, *Vice President*

Pam Steneberg
Disability Rights Education & Defense Fund, Berkeley, CA, *Secretary*

Janet Voha
Federation for Children with Special Needs, Boston, MA

Patricia Smith
Executive Director

782

Clinician's View Video Collection

Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices.The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays,

by Susanne R. Hays, M.S.,R.N.,C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. **ED 077OD**

Effective Intervention For Self-Feeding Success,

by Christine A. Nelson, Ph.D.,OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. **ED 078OD**

Massage For The Infant With Developmental Disabilities,

by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant's individual concerns. A valued resource for every parent to assist their child's development.

ED 079DD

Near Normal Feeding For Infants With Oral-Facial Anomalies,

by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant's born with cleft lip and/or palate can be very difficult.Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies that parents can follow. **ED 080OD**

Mail to: **Exceptional Parent,** Dept. EP9410, P.O. Box 8045, Brick, NJ 08723
Or call **1-(800) 535-1910**

QTY	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. - $3.50 for 1 item; 75¢ for each additional item. Foreign - $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
N.J. Res 6% tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

I have enclosed my check payable to Exceptional Parent or charge to my: Visa Mastercard

Account Number: _____ Exp. Date: _____

Signature 785 _____

Circle # 227

NEW PRODUCTS

FREEDOM

Go here, go there, go anywhere in any weather! This all-terrain, battery-powered go-cart handles snow, gravel, hills or sand to get children around. The child controls the go-cart through a sip-n-puff switch, head control, or joystick. An automatic lift enables easy transfers. Balloon tires and a low center of gravity offer stability. Five-point harness seat belts keep the rider secure.
Tibby's, Duncan, BC, Canada V9L 3W8

Circle # 276

11P TRAY/DESK

Perfect for the student wheelchair user! This full-size clear plastic wheelchair tray with stomach cutout lifts to reveal a storage desk with various compartments. Easily installed and removed by means of telescoping support arms suitable for most wheelchairs. A keyed lock is available to protect items in the desk.
Consumer Care Products Inc., Sheboygan, WI 53082

Circle # 277

WANDER ALERT SYSTEM

For wandering toddlers, there is no longer any need to keep constant watch or to "tag" kids with bracelets or collars. This perimeter alert system can be used not only in the house, but also around swimming pools and other areas hazardous to toddlers. The system consists of an electronic perimeter detection and a personal pager—no frightening loud alarms. Options allow the system to work as an emergency response device, burglar alarm or fire alarm.
Safe and Sound Homecare, Lincoln, NE 68502

Circle # 278

FANLIGHT EDUCATIONAL AND AWARENESS VIDEOS

Documentary-style videos feature children and adults with disabilities who show the potential each individual possesses. The stories focus on people who put emphasis on their abilities, not their disabilities. Find out how deaf children learn to communicate; see how kids with disabilities play; learn about autism; share the experiences of children with cancer at camp and hear from siblings of children with lung disease. Each video sold or rented separately. Many are open/closed-captioned.
Fanlight Productions, Boston, MA 02130

Circle # 279

REJOICE FOR CHILDREN

A better choice in incontinence pants! These side-closing or pull-up style pants are ideal for children with light to heavy incontinence. The pants have a disposable insert liner made of a patented material that is attached to a thin, comfortable cotton pant. Plastic-free (no rustling noise!), these are not diapers, so kids can feel better about wearing them. Ask manufacturer for a free liner sample.
C.P. International Inc., New York, NY 10177

Circle # 280

COMPUTER SPACE STATION

This system of brackets, trays and tracks may be mounted on almost any vertical surface (walls, partitions, cubicles, file cabinets, etc.) to provide a wheelchair-accessible work station. The user can customize the configuration to meet specific needs. Trays for the monitor and keyboard are height- and swivel-adjustable. Saves space and creates a comfortable work area for every student.
Support Engineering Associates, Garden City, NJ 11530

Circle # 281

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

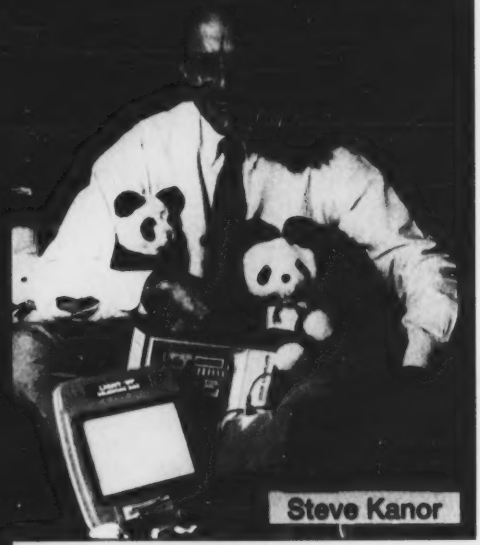
784

Toys for Special Children

The people of Toys for Special Children have sought to create a new world of play for the handicapped through the development of specially adapted toys, capability switches, activity centers, augmentative communication aids, and countless other special devices for the handicapped.

Vibrating Light

Call 800-832-8697


Steve Kanor

Special Service

We offer many standard technical solutions for handicapped people. We realize that for some, special adaptions are needed. Please call us so that we can discuss fabricating custom equipment for your special requirements.

"Dr. Kanor's devices have benefits beyond words"

-The New York Times-
Oct. 20th, 1991

A unique resource for technology which can be used to increase, maintain, or improve functional capabilities of individuals with disabilities.

The Cooper Car

To get your catalog call or write to:
Toys for Special Children
385 Warburton Avenue
Hasting-on-Hudson, NY 10706
800-832-8697

Circle # 194

EXCEPTIONAL PARENT *Library*

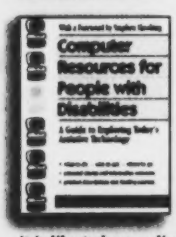
You can order any of the books listed here with the coupon below or by calling (800) 535-1910

DISABILITY, GENERAL

ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
BY TONI FLOWERS
Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels.
PE035OD **$29.00**

ATTENTION DEFICIT DISORDER: ADHD & ADD SYNDROMES (2nd ed.)
DALE R. JORDAN
Guidelines for working successfully with ADHD and ADD in children, adolescents, and adults. For teachers, counselors, and parents.
PE038AD (book) **$14.00**
PE038 (tape) **$98.00**

THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
HC082OD **$12.00**



COMPUTER RESOURCES FOR PEOPLE WITH DISABILITES: *A Guide to Exploring Today's Assistive Technology*
THE ALLIANCE FOR TECHNOLOGY ACCESS
This book will show you how today's technology is redefining human potential and what it is like to have a disability. It provides user-friendly support, information, and up-to-date answers.
HP087OD **$14.95**

DISABILITY AND THE FAMILY
A Guide to Decisions for Adulthood
H. TURNBULL, ET AL.
This practical, easy-to-use guide helps answer families' questions concerning the future needs of their family members with disabilities.
PB054OD **$29.00**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: *Directories of National Organizations, Associations, Products & Services*
A valuable reference tool for parents and professionals.
EP055DR **$20.45**

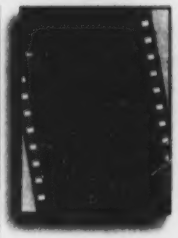
HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder

L. ADKINS & J. CADY
Information about typical behavior characteristics; suggestions on how to foster the development of appropriate behavior.
PE040AD (book) **$5.00**
PE040 (tape) **$89.00**

HONOR THY SON
A novel by Edgar Award winner Lou Shaw
This unforgettable story combines suspense, terror and international intrigue—and a father and a son each pursuing a dream.
AB081OD **$12.95**

I AM, I CAN, I WILL
MISTER ROGERS
A series of audio and printed materials designed for young children with disabilities. These programs may be used to help develop a child's emotional, language, perceptual, listening and creative abilities.
15 tapes & 5 books
PE056OD **$119.00**

I WISH...
Dreams & Realities of Parenting a Special Needs Child
KATE DIVINE MCANANEY
A book about conflict, courage and creative solutions.
CP074CP **$8.95**



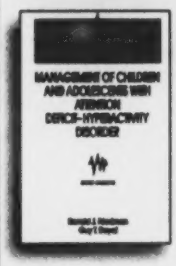
THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
EP001EP **$14.95**

THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
WB020OD **$14.95**

LITTLE CHILDREN, BIG NEEDS: *Parents Discuss Raising Children with Exceptional Needs*
DON WEINHOUSE, PH.D. AND MARILYN WEINHOUSE, M.A.
What are the concerns of parents who raise disabled children? This question is addressed through candid interviews with 50 families of children with a wide range of disabilities.
RUP068OD **$12.95**

MAKING CHANGES
Family Voices on Living with Disabilities
JAN A. SPIEGLE
Shares self-reports and visions on how families and professionals make changes.
BL061OD **$19.95**



MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH ADHD
Third Edition
RONALD J. FRIEDMAN & GUY T. DOYAL
The most current medical and psychological research findings with 20 years' clinical experience. Written in a clear, nontechnical manner.
PE039AD **$24.00**

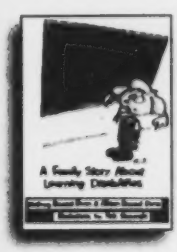
OUT OF SILENCE
A journey into language
RUSSELL MARTIN
A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.
HH083AM **$22.50**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP02100 **$75.50**

PLANNING FOR THE FUTURE
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP02400 **$24.95**

SIBSHOPS
Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB08600 **$32.00**

THAT ALL MAY WORSHIP
An Interfaith Welcome to People with Disabilities
GINNY THORNBURGH
An interfaith handbook to assist congregations in welcoming people with disabilities to promote acceptance and full participation.
ND08400 **$10.00**



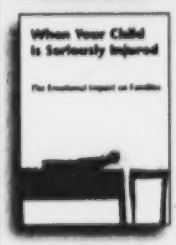
TROUBLE WITH SCHOOL
A Family Story About Learning Disabilities
ALLISON & KATHRYN DUNN
This book takes a clear look at the warning signs and common problems associated with LD.
WB028LD **$9.95**

THE WHEELCHAIR TRAVELER
DOUGLASS R. ANNAND
A practical dictionary of information for the traveler with a disability. Includes accessibility ratings of hotels/motels in the U.S., Canada and Mexico and useful tips for parents.
WT015PD **$20.00**

INJURY

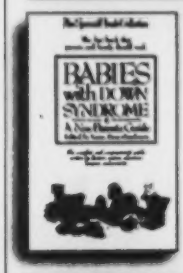
WHEN YOUNG CHILDREN ARE INJURED: *Families as Caregivers in Hospitals and at Home*
J. HALTIWANGER & M. LASH
A book about the family's role in caregiving when a young child is injured.
EP085ML **$7.50**

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$7.50**



WHEN YOUR CHILD IS SERIOUSLY INJURED
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$4.50**

MENTAL RETARDATION



BABIES WITH DOWN SYNDROME
A Parents' Guide
ED. BY KARIN STRAI-GUNDERSEN
The complete guide for new parents of babies with Down Syndrome. Written by professionals and parents, this book covers everything new parents need to know.
WB010MR **$14.95**

THE CHILD WHO NEVER GREW
PEARL BUCK
Brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation.
WB006MR **$14.95**

THE CONQUEST OF MENTAL RETARDATION
BURTON BLATT
Basics of the field—history, classification, and definitions—but also discusses controversies: nature vs. nurture, deinstitutionalization vs. institutionalization, and the educability hypothesis.
PE047MR **(hard) $38.00**

SPEAKEASY
People With Mental Handicaps Talk About Their Lives in Institutions and in the Community
KARIN MELBERG SCHWIER
People labeled mentally handicapped speak honestly and powerfully about their lives in institutions and in the community.
PE044MR **$16.00**

Mail to: **Exceptional Parent,** Dept. EP9410, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents add 6% Sales Tax	
Shipping	
TOTAL	

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _____ - _____ - _____ - _____ Exp. Date ____/____

Signature _____

787

Circle #300 to receive a brochure of the complete library

CHILDREN'S PAGE

MY NEW BROTHER

by Bryan Welch

My 12-year-old stepbrother Forrest, Forrest's dad, my mom and I all got married one year ago. We were all part of the wedding, so Mom says we all got married into a family. I kind of like that idea now, but at first I didn't. You see, Mom and I were together for seven years—just the two of us. Whenever I wanted some attention from her, I got it. Now, I have to share Mom with Forrest.

Forrest has Down syndrome. Many people don't understand him when he talks or acts out his feelings in public. Kids who have Down syndrome are all different; my brother doesn't seem to have it as bad as another kid in our school. My mom had to tell my grandma that Forrest is not the way he is because of his real mom and dad, that Down syndrome could happen in any family. She had to explain that to a lot of other parents, too. People really don't understand about Down syndrome until someone explains it.

Forrest, Mom and Bryan share a happy moment during the new family's honeymoon trip.

Sometimes I get a little upset because I think Mom praises Forrest more than me—like one time when Mom let Forrest and me walk to the post office by ourselves and Mom told Forrest she was proud of him for looking both ways before crossing the street. My feelings were hurt until Mom explained that she knows *I* look both ways before crossing the street, but she had never seen Forrest do it before. Her explanation made sense because Mom taught me a long time ago that I should look both ways before crossing, but she just started teaching Forrest.

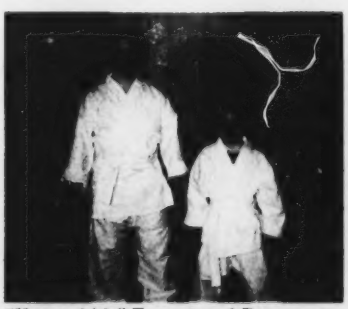
At school, some kids tease me for being Forrest's little brother. When that happens, I do what Mom told me to do—I put my hands on my hips and say, "*You* don't know Forrest!" Then I walk away.

Sometimes, kids tease Forrest, too. Mom is teaching him to say, "I'm mad at you," and then walk away. Most kids in school really like Forrest and me. We don't get teased too much.

Forrest is fun to play with. We make all sorts of things together. We like to gang up and tease Mom. Forrest plays basketball really well, better than a lot of other kids. And he sure can bat when we play baseball. He makes home runs every time! He bats and I run.

Forrest is a real cool brother. I love him very much.

Bryan's new family: *Bryan's mother and Forrest's father got married on June 2, 1992. Clockwise from left: best man Gerald Leach, groom Forrest Wilson Sr., bride Eileen Wilson, Melissa Wilson, 18, Bryan Welch, 7, and Forrest Wilson Jr., 11.*



"Karate kids" Forrest and Bryan enjoy participating in sports together.

Bryan Welch, 8, lives in Zillah, Washington. He is a second-grader at Hilton Elementary School. He enjoys track, basketball, baseball, swimming, dirt-bike racing, go-cart racing, camping, fishing and karate. He collects sports cards and is an avid chess player.

Forrest is in the fifth grade at Hilton Elementary School. He has been included in Zillah public schools since kindergarten. He plays drums in the school band, and also takes guitar lessons. He is involved with his school's track team and is also a member of the Mustangs, a basketball team specializing in trick shots.

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to:

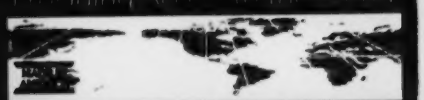
Children's Page
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005

788

BRAUN

THE ANSWER TO ALL YOUR MOBILITY NEEDS.

U



1-800-THE LIFT

©1994 BISSELL Healthcare Corporation J2170 9/94

Tumble Forms

Happy Holidays
from
Tumble Forms.

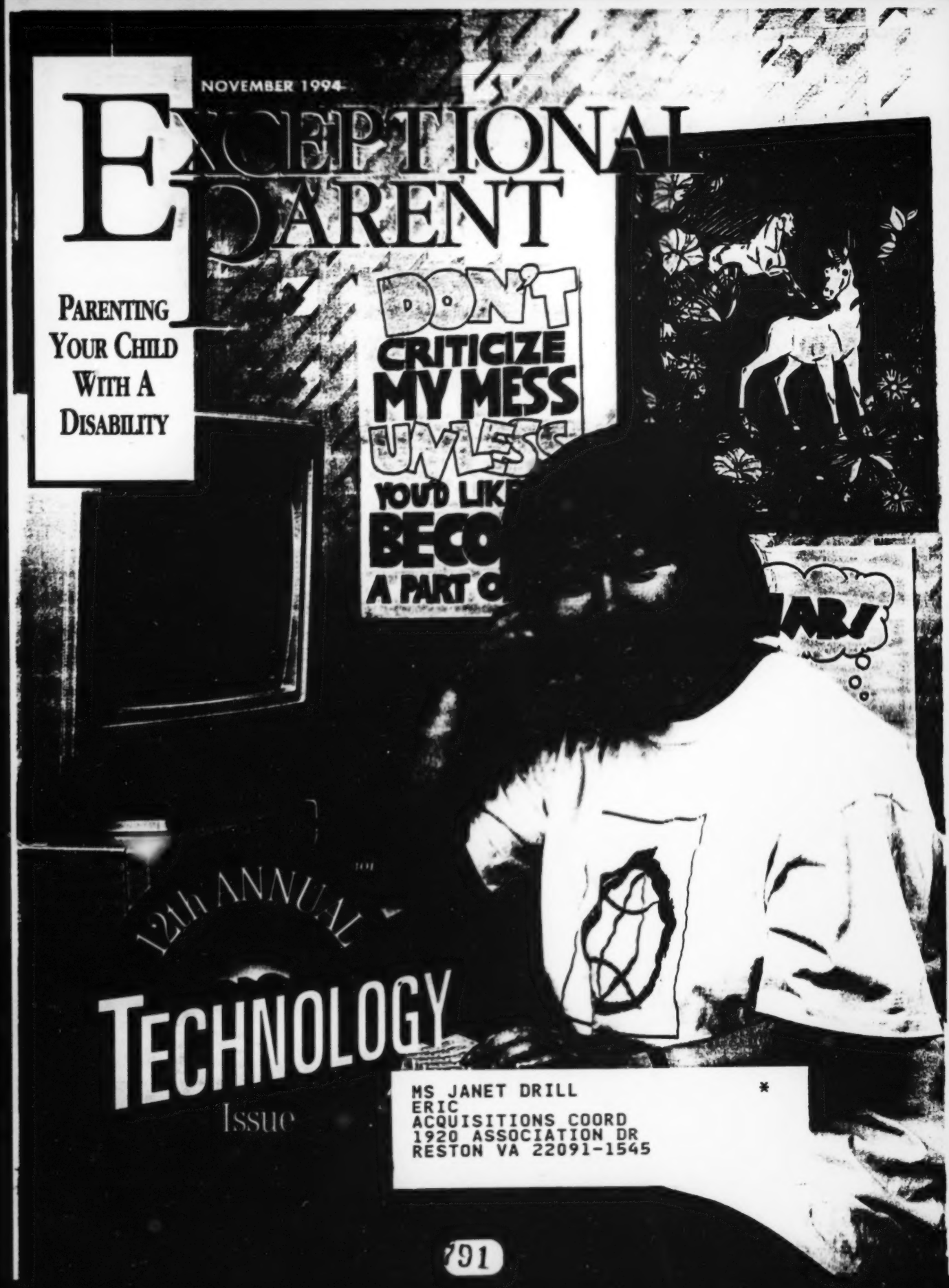
We'll brighten your holiday season with a free subscription or renewal to *Exceptional Parent* Magazine when you order any of our Tumble Forms products. Simply mark your warranty card, Holiday Promotion* and send it to us.* This will activate your subscription.

But wait, there's more bright news! You'll also receive redeemable Tumble Forms dollars, good towards future Tumble Forms purchases.

For more information call J.A. Preston Corporation
In U.S.A. 1-800-631-7277.
In Canada call 1-800-665-9200.

* To qualify orders must be made on or before December 18, 1994 and warranty cards must be postmarked on or before April 30, 1995.

Circle # 7 790



MS JANET DRILL *
ERIC
ACQUISITIONS COORD
1920 ASSOCIATION DR
RESTON VA 22091-1545

It's time for you to speak your mind...

Imagine not being able to express one's own thoughts so that others may understand.

Now with a Canon CC-7S or CC-7P Communicator, anyone's dream of being heard can come true.

These electronic aids allow people who are hearing and speech disabled or motor handicapped to effectively communicate in their daily lives.

Designed for easy use, all of the Canon Communicator's operations can be accomplished by using the keyboard to type and then print out messages onto thermal tape for easy readability.

With the Canon CC-7S Communicator, you can record a total of 240 seconds of speech under 26 locations–alphabet keys–using the supplied microphone. Playback is accomplished through the built-in speaker.

Message memory enables the user to store up to 7000 characters under the 26 alphabet keys in memory. This allows for rapid printouts of frequently used phrases. With the CC-7S Communicator, it is also possible to program the message memory for simultaneous sound playback and tape printout.

The single-key operation mode helps those who found striking specific keys difficult. Keys can be selected by simply designating the row and column which intersect at the desired key using the indicator lamps on the keyboard's right and bottom edges. All of the Communicator functions can be used in this special mode.

And because each Communicator can be strapped on to a wrist, a wheelchair, a bed rail, with a battery pack or AC cord, they can be used wherever they may be needed.

In addition, there are Canon Factory Service Centers throughout the world. And the Canon Communicator gets first priority whenever it is brought in for service. Because Canon knows that no one should be deprived of the power to speak their mind and to be heard.

CANON COMMUNICATOR

CC-7P **CC-7S**

To receive your free information about the Canon Communicator CC-7S and CC-7P, please complete this form and mail to:

Canon U.S.A., Inc. Home Office Products Division
One Canon Plaza, Lake Success, NY 11042

Name (Please Print) _____

Address _____

City _____ State _____ Zip _____

Phone _____

782

Canon

© 1988 Canon U.S.A. Inc.

Circle # 294

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

NOVEMBER 1994
VOL. 24, ISSUE 11

PAGE 45

COVER:

During the school year, 18-year-old Nhi Duong uses a home computer and the Internet to keep in touch with friends she made during the DO-IT (Disabilities, Opportunities, Internetworking and Technology) summer session at the University of Washington in Seattle. Nhi, a senior at Evergreen High School in Seattle, has multiple sclerosis and is legally blind. Born in Vietnam, Nhi moved to the U.S. in 1984. A story about the DO-IT program begins on page 33. Photograph by Mary Levin, University of Washington.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005.

All rights reserved, Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation.

POSTMASTER: Please send address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year. Annual subscription rate for Canada is $30 (U.S. funds only); All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE:** Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service, Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries:* No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

TECHNOLOGY

Real People, Real Technology, Real Solutions 20

Alliance For Technology Access Update by Jacquelyn Brand 22
A focus on some of the Alliance's key national initiatives.

Alliance For Technology Access Directory 26

GUEST EDITORIAL: Too Few Exceptions to the Rule
by Bob Williams *A vision of true technology access for all,* 31

Disabilities, Opportunities, Internetworking & Technology = DO-IT! by Sheryl Burgstahler 33
Technology gives high school students access to science, engineering and math.

FEATURES

Using Ordinary Toys for Kids with Special Needs
by Joanne and Stephanie Oppenheim 42

Song of Light by Susan L. Gengerke 45
A mother sees her son for what he is, not for what he lacks.

More Sibling Concerns by Donald J. Meyer 49

Environmental Controls by Carole Lendosky 51

Dental Care for Children with Disabilities by Steven P. Perlman 53
PART FOUR: Common Pediatric Dental Problems.

DEPARTMENTS

Editor's Desk 2

Letters 4

Search & Respond 8

Familiar Faces 16

Ask the Doctor: "FLU" AND "PNEUMONIA" VACCINES 19

Role Models: ROBERT WALSH 37

Fathers' Voices: A WHOLE NEW BALLGAME by James May 55

Directory of Advertisers 62

Health Insurance Troubleshooter: AUGMENTATIVE COMMUNICATION DEVICES 68

What's Happening 70

New Products 73

Exceptional Parent Library 74

Children's Page: JOSEPH by Teresa Schubert 76

EDITOR'S DESK

Attention readers! Prepare yourselves for an emotionally bumpy trip through our 12th Annual Technology Issue. Incredible and wonderful things are happening as more and more children and adults with disabilities access the powers of modern technology. But be prepared for a mixture of feelings—so much of this technology still feels so far out of reach, and so much remains expensive.

STANLEY D. KLEIN, PH.D.

It can be overwhelming to consider the pace of change and the impact of technology in our lives. Bob Williams, commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services ("Too Few Exceptions to the Rule") and this issue's *Role Model*, Robert Walsh, both emphasize the importance of technology to full participation in community life. They show how important it has become to learn to harness the power of technology in our everyday lives. Yet many of us may wonder if we actually have the energy to learn any of this stuff.

We appreciate the work of Jackie Brand, executive director of and long-time driving force behind the Foundation for Technology Access, in pulling together the stories you will read in "Real People, Real Technology, Real Solutions." Sheryl Burgstahler's article about the DO-IT program provides even more examples of the way technology access can help children with disabilities overcome many of the attitudinal barriers unnecessarily imposed on their aspirations. These stories are exciting! It is incredible to see how children with disabilities—infants, toddlers, school-age kids and teens—are learning to use technology! It is also frustrating and frightening because so many still do not have access to these opportunities.

In our first Technology Issue back in 1983, we noted that "an estimated $63.5 billion per year is spent to provide financial support for adults with disabilities who are dependent on public funds for food, shelter, medical care and other services. We have no way of knowing how many of these people might be able to care for themselves or even hold jobs with the right aids and training, but it is clear that widespread application of the latest technology could accomplish a great deal."

Looking back, we can see how much has already been accomplished. Yet as Bob Williams reminds us, we must work to assure that people like himself or Bobby Walsh are no longer exceptions, and that every child with a disability may share the opportunities of technology.

In the spirit of giving

On rare occasions in the past 23 years, this column has mentioned a specific manufacturer; this is one of those occasions. In an advertisement in our October issue and in several other publications, wheelchair manufacturer Kuschall of America announced a plan to make holiday gifts of 20 new wheelchairs to individuals in the United States and Canada who might not otherwise be able to obtain them. Within one month after this announcement, the following companies had joined Kuschall of America in this venture: Freedom Design, Jay Medical, Kid-Kart, LaBac Systems, Pindot Products, Prime Engineering, Rhamdec, Roho and Special Health Systems. Together, these companies will donate holiday gifts with a retail value of more than $200,000. *Exceptional Parent* will join this effort by donating a gift subscription to each recipient of a holiday gift from this program.

I can appreciate that many consumers may have mixed feelings about this type of corporate gift-giving. Yet, to my knowledge, this has never happened before in any season. I congratulate the participating manufacturers for demonstrating that one person and one company can make a difference.

Happy Thanksgiving.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology
New England College of Optometry

ASSISTANT EDITOR Kim Schive

EDITORIAL STAFF
Marc S. Malkin Leslye Smucker

EDITORIAL INTERNS
Andrea Kamens Jennifer M. Koerber
Sylvia Wagner

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5006
(617) 730-5800 Fax (617) 730-5742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Suters

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferrante

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (CO, IN, KS, MN, MO, So OH, SD, UT, WI)
Anthony Arsone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, MI, MO, NE, No OH)
John Maisel
(708) 416-0780 Fax (708) 416-0783

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, ID, MT, OR, WA, WY, BC)
William Hagler
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESOURCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

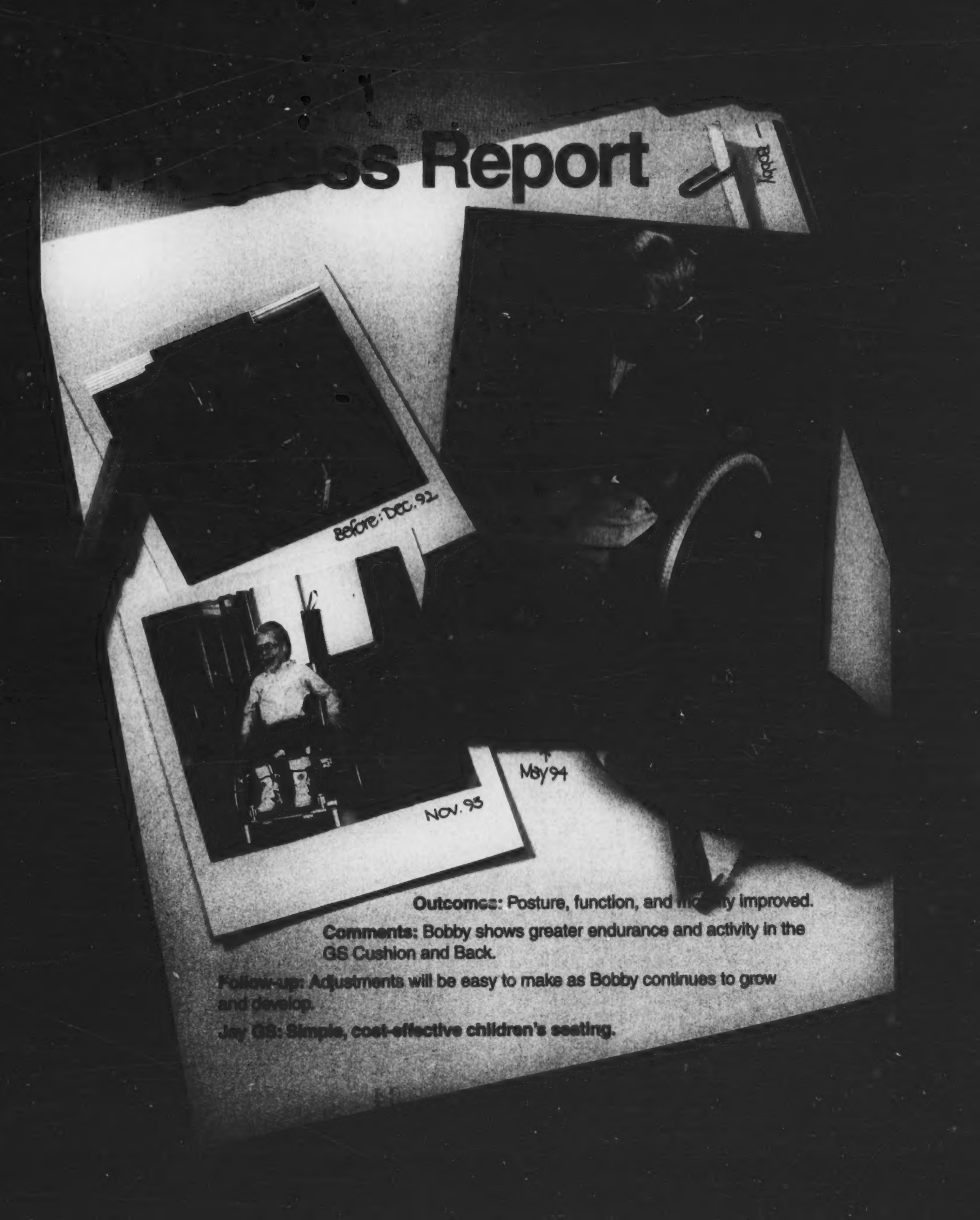
COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 62. EPA International Consumer Magazine Membership Applied for August 1993.

794

ss Report



Outcomes: Posture, function, and m[illegible]y improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

LETTERS

Inclusion Article Misleading

I read "Making Inclusion Work" (September 1994) with interest. Mrs. Hart is to be commended for her accomplishments with her daughter, Angela.

My son is an inclusionary student as well, and I know that the amenities afforded to the Harts—like 30-member "circle of friends" meetings and four-times-per-year child study team conferences—are not available to the average family. My husband and I couldn't persuade our child study team to meet with us at all, except for the annual review.

I find it difficult to believe that one could persuade Brownie leaders, soccer coaches, a principal and others to care enough to attend a meeting about coordinating all aspects of a child's life. Obviously, the Harts have been successful in this endeavor, but I cannot imagine this as a realistic scenario for most families of children with disabilities. For most children with disabilities, positive extracurricular experiences are rare. Usually, the child is not accepted or wanted by other children, the achievement-oriented parents of these children and the facilitators of the activity. Participation in sports is reduced to the child donning a uniform and being permitted to attend practices and games as a sort of team mascot.

The article does not accurately reflect the struggles of most families who have a child with a disability. Please include articles in your magazine that will help average families deal with the special education system. The reality of the system includes continually decreasing funding and child study teams that are overloaded with cases. Most children will not get the attention afforded to Angela Hart. This misleading article will result in disappointment and disillusionment for families trying their best to cope.

J.R., New Jersey

Fluoride Rinse

In regard to the article on dental care for children with disabilities ("Brushing, Flossing and Rinsing," September 1994), I am concerned with Dr. Perlman's suggestion to use a fluoride rinse on a child who cannot spit or rinse without swallowing. As suggested by my dentist, I used a fluoride rinse on my three-year-old's teeth; within five minutes, he vomited. I find it best to brush his teeth with a small amount of toothpaste and rinse using my finger covered by a wet washcloth.

Fluoride rinses carry a warning that they should not be swallowed. So, I advise caution if there is a chance your child may swallow even a small amount.

E.M.C., New York

EDITOR'S NOTE: Dr. Perlman's article did not recommend that fluoride rinse be used in the usual manner for a

Tell us about...

...your experiences with the IEP process.

(What changes would you make?)

Write to: *IEP Meetings, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax).*

A sampling of reader responses to this question will appear in a future issue.

EXCEPTIONAL PARENT

- *To reach out to parents of children with disabilities and special health care needs.*
- *To empower mothers and fathers by providing practical information and emotional support.*

EDITORIAL ADVISORY BOARD

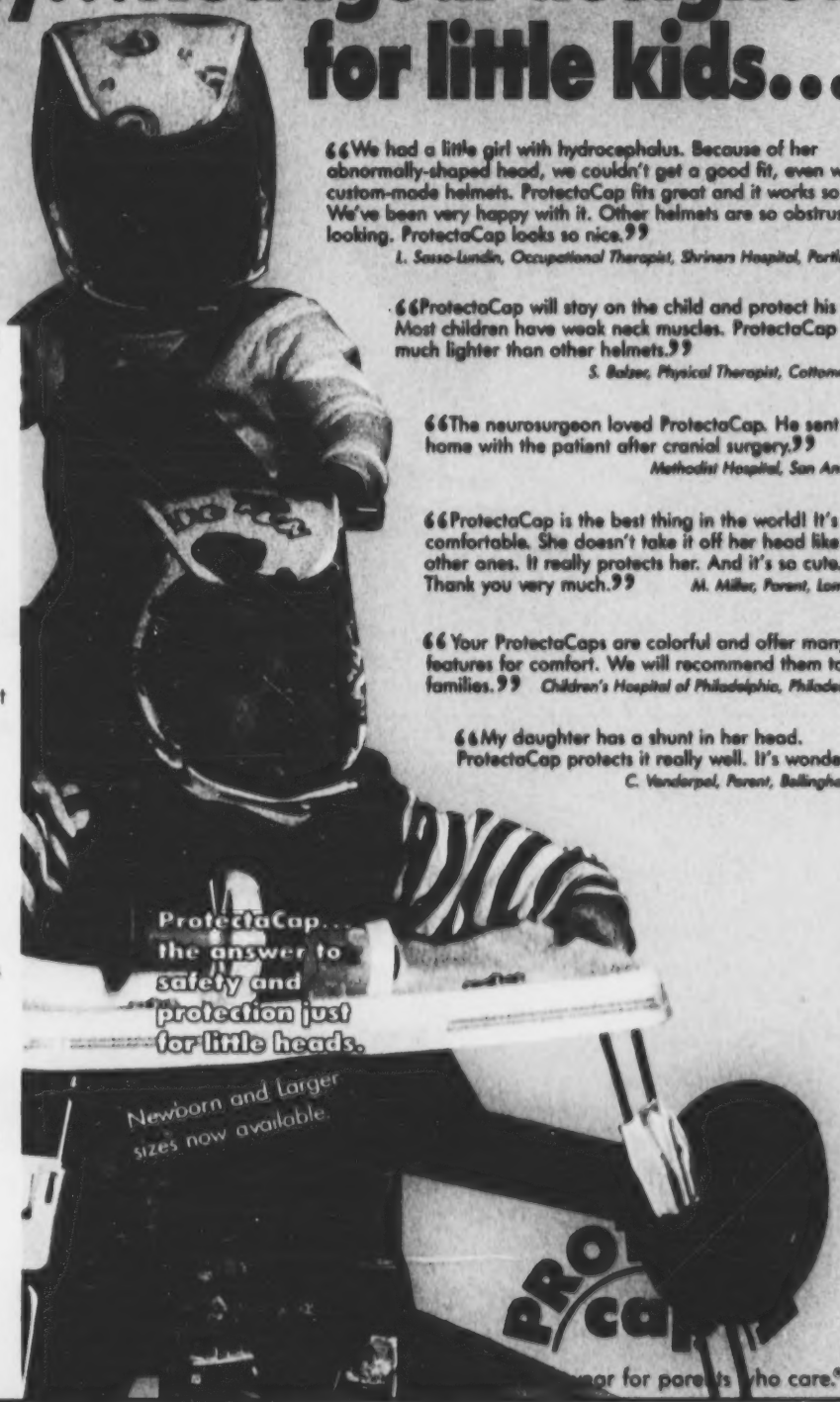
LISA BLUMBERG, J.D., Corporate Attorney, Aetna, Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Waltham, MA
SANDRA B. FLEISHMAN, Parent, Project Director, A WORLD OF DIFFERENCE Institute, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, Pomona, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President Emeritus, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

796

Finally...Headgear designed just for little kids...

And the healthcare professionals' answer to safety.

ProtectaCap® is ideal for post-surgery and therapeutic activities. ProtectaCap is made with proven shock-absorbent Ensolite® foam which helps to prevent injury by absorbing the impact of a blow or fall. ProtectaCap's unique, expandable design provides a comfortable, custom fit for each child under six years of age. And ProtectaCap weighs only three ounces. Tested by safety engineers, ProtectaCap rates "excellent" in shock absorption. It replaces hard plastic by eliminating weight, heat, bacteria and discomfort. Little heads are secured quickly with a convenient Velcro® closure. And ProtectaCap is fully machine-washable. ProtectaCap is cute, colorful, and adds to the self-esteem of any child requiring headgear.



"We had a little girl with hydrocephalus. Because of her abnormally-shaped head, we couldn't get a good fit, even with custom-made helmets. ProtectaCap fits great and it works so well. We've been very happy with it. Other helmets are so obstrusive-looking. ProtectaCap looks so nice."
L. Sasso-Lundin, Occupational Therapist, Shriners Hospital, Portland, OR

"ProtectaCap will stay on the child and protect his head. Most children have weak neck muscles. ProtectaCap is so much lighter than other helmets."
S. Balzer, Physical Therapist, Cottonwood, AZ

"The neurosurgeon loved ProtectaCap. He sent it home with the patient after cranial surgery."
Methodist Hospital, San Antonio, TX

"ProtectaCap is the best thing in the world! It's so comfortable. She doesn't take it off her head like the other ones. It really protects her. And it's so cute. Thank you very much."
M. Miller, Parent, Lombard, IL

"Your ProtectaCaps are colorful and offer many good features for comfort. We will recommend them to our families."
Children's Hospital of Philadelphia, Philadelphia, PA

"My daughter has a shunt in her head. ProtectaCap protects it really well. It's wonderful."
C. Vanderpol, Parent, Bellingham, WA

PRO[illegible]ca[illegible]

[illegible]nor for pare[illegible]who care.®

• Yellow • Pink • Light Blue • Royal Blue • Neon Pink
• Neon Green • Neon Pink/Black • Neon Green/Black
• Royal Blue/Silver • Boy Print • Girl Print

Manufactured and Sold Exclusively by:

pl[illegible]
e[illegible]prises, Inc.
9 Clyston Circle
P.O. Box 283
Worcester, PA 19490

Order Now-Call TOLL FREE

1-800-321-PLUM

or Fax your order to 215-584-4151

[illegible] ACCEPTED. OVERNIGHT DELIVERY AVAILABLE

$72.95, plus $7.95 S/H. **MEDICAID APPROVED.**

Circle # 239

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

Haverich ORTHOPAEDIC CYCLES

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.

Circle # 36

child who cannot rinse and spit without swallowing. For such a child, the article specifically recommends that the caregiver put a little fluoride rinse on the end of a q-tip which can be swabbed over the child's teeth.

Professional Praise

This letter is long overdue. I am a professional who, since 1965, has been involved in training all levels of staff who deliver services to individuals with developmental disabilities. In addition, I recently became the facilitator for a parent support group.

I cannot stress the importance of the assistance I have received from *Exceptional Parent.* The articles, letters from parents and special departments in each issue have been invaluable. I find more helpful information in this magazine than I do in the professional journals I read.

Please keep up the good work. Parents who subscribe call the magazine their "bible."

M.K.M., Georgia

Spreading the Word

As usual, I read the September issue cover to cover. When I saw your request to spread the word about the magazine, I wrote an article which will be published in my daughter's school newsletter. It begins like this: "Like all busy parents, you probably do not find much time to read. However, as parents of children with special needs, there is one monthly publication I would encourage you to make time for. It is called *Exceptional Parent...*" I went on to describe the regular features of the magazine and give subscription information.

I wanted to share this idea as an example to other parents who also may wish to spread the word about *Exceptional Parent* through their child's school publication.

Thank you very much for your excellent magazine.

E.K.L., New York

EDITOR'S NOTE: Thank you for sharing your idea with us. We continually hear from new readers who say they don't know why they hadn't heard of the magazine sooner. Thanks for helping to get the word out.

123 123 123 123 123

ABC

Where kids can be kids!

Prescribed daycare facility
for medically complex children
Ages 3 months - 7 years

- Skilled Nursing Care
- Therapy Services
- Educational Development
- Infusion Therapy
- Interaction with other children in a developmentally stimulating environment

Tomorrow's Child
CENTERS FOR MEDICALLY DEPENDENT CHILDREN

Centers nationally located. For information call
(609) 354-9106

123 123 123 123 123

Circle # 215

798

PRODUCT NEWS

Lightweight Portability Solves Transport Problem

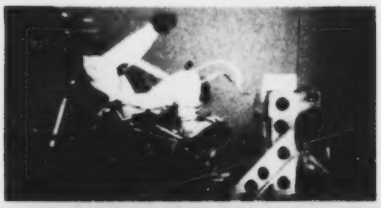
Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

Full Range of Accessories

A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

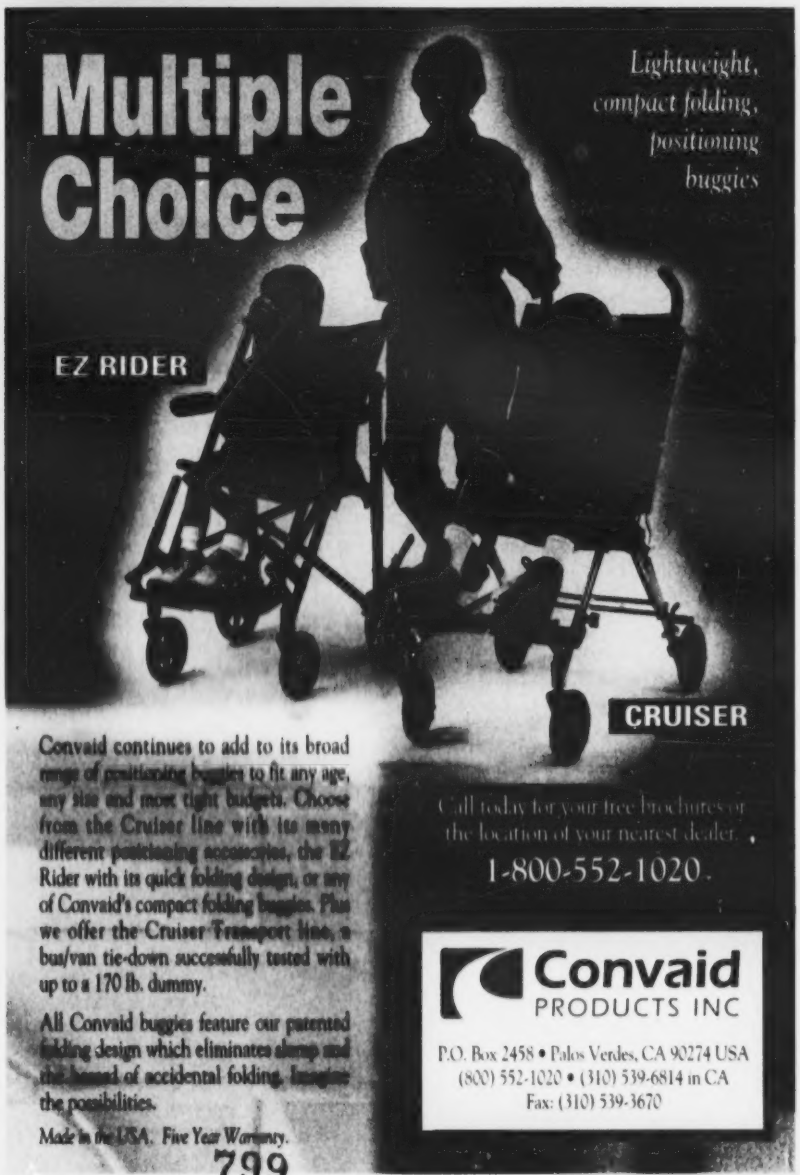
New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.



Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability. .


Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.
All Convaid buggies feature our patented folding design which eliminates slump and the hazard of accidental folding. Imagine the possibilities.
Made in the USA. Five Year Warranty.
Call today for your free brochures or the location of your nearest dealer.
1-800-552-1020.
Convaid
PRODUCTS INC
P.O. Box 2458 • Palos Verdes, CA 90274 USA
(800) 552-1020 • (310) 539-6814 in CA
Fax: (310) 539-3670

Circle #16

SEARCH

Non-Organic Failure to Thrive

My two-and-a-half-year-old son has been diagnosed with non-organic failure to thrive. At first, doctors said he was experiencing a behavioral feeding difficulty. I had a hard time accepting this. Eight months ago, he had complete gastrointestinal and endocrine evaluations that were inconclusive, except for finding the parasite giardia. He has been fed with an NG-tube for the last six months but has experienced little growth; currently he has a Mic-Key G-tube. I would love to hear from anyone with a similar child.

C.C., Washington

Stepparent Seeks Insurance Information

I am the stepmother of a five-year-old boy who was born with multiple disabilities. Born prematurely (at 34 weeks gestation) after an otherwise normal pregnancy, Chris has been diagnosed with cerebral palsy, spina bifida, dual lower-eyelid coloboma (clefts), hydrocephalus, two–three toe syndactyly, dual hernias, a high double-grooved palate and a multi-cystic kidney. He had some seizure activity at birth. No syndrome has been identified. All chromosomes are normal.

We are trying to get health insurance coverage for Chris. At the time of his birth and related surgeries (the last one was in May 1992), Chris was covered under the U.S. military medical plan, but my husband is no longer in the military. Despite the fact that Chris' birth problems have all been corrected (to the extent that they can be), we have been unable to find insurance that will cover Chris with his "pre-existing conditions." We want coverage only for "normal" childhood illnesses and injuries. Does anyone know of an insurance plan that looks favorably on children with disabilities?

Chris' father and I have been raising him since he was two years old (my husband has full legal custody). Chris lives with us during the school year and visits his mother and stepfather during the summer months. In spite of his lengthy list of disabilities, Chris has progressed remarkably well. He is enrolled in a public school special education kindergarten class and enjoys the activities of other children his age. He also spent two years in an early intervention program and Head Start. His medical conditions have all been resolved. Chris looks "different," but after the initial stares by other children, they accept him like any other child. He is extremely outgoing.

I would be very interested in corresponding with parents who have a child with similar conditions, or other stepparents of children with any disability.

M.S., California

Communication Frustrations

My nine-year-old son, Scott, is currently included in the first grade in a small rural community. Scott has spastic quadriplegia cerebral palsy and uses an augmentative communication device (the Liberator) for his academic and communication needs. He currently accesses his Liberator by scanning, and may eventually graduate to the use of an infrared light. Scott was very successful in kindergarten last year. By the end of the year, he was well on his way to learning his alphabet and some letter sounds. He also enjoyed socializing with the other children.

However, this year has been very frustrating for Scott and his teachers, therapists and parents. He seems to get upset and frustrated very easily, especially with his Liberator. He is the only student in the entire school with this degree of disability, so this is a new experience for everyone.

I would like to hear from other parents who are in a similar situation, and would appreciate some new ideas from people who have experience in maintaining an augmentative communication device. I also would appreciate hearing about anyone who is currently using a different augmentative communication system with some success.

C.D., Illinois

Pfeiffer Syndrome

We are the parents of an outgoing, energetic two-year-old named Bryson. He has Pfeiffer syndrome (a craniofacial disorder) and hydrocephalus. Bryson has had seven surgeries including one shunt placement.

We are interested in the genetic aspects of Pfeiffer syndrome. How many children in the United States have it? Is it linked to a chromosomal abnormality? If so, which one? Could it be diagnosed with amniocentesis?

We also are interested in exchanging letters with other families of children who have Pfeiffer syndrome.

B.H. & M.H., North Carolina

Down Syndrome and Blind

I have a daughter who is a little over one year. At birth, Morgan was diagnosed with Down syndrome and several heart problems. This was unexpected and devastating news. But before it even had time to sink in, Morgan was also diagnosed with a cancerous brain tumor (astrocytoma). Morgan was two and a half months old when she was admitted to the hospital for a long stay in which she fought for her life. It is a miracle she made it. As a result of the cancer, however, she is completely blind.

I have been unable to find anyone else dealing with this combination of problems. Is there anyone out there who has a child like mine?

A.R.G., North Carolina

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5006
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

800

Bed-wetting won't bother him tonight. And you can't see why.

Pull-Ups® GoodNites™ absorbent underpants are the first ones ever made for bigger children–45 pounds and up.

They're superabsorbent, yet so thin, they all but disappear under pajamas.

The child slips them on and–accident or not–wakes in a clean, dry bed. With a whole new positive attitude.

GoodNites™ will help keep kids dry until they outgrow bed-wetting. Since 3 million kids share this problem, that's a lot of good mornings.

Get the GoodNites™ Guide for Kids–yours for sending just $1 postage and handling to: GoodNites™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

® Registered trademark of Kimberly-Clark Corporation. © 1994 KCC

"GoodNites™ mean Good Mornings."

Circle # 147

801

BRAUN

THE ANSWER TO ALL YOUR MOBILITY NEEDS.

ENTERVAN™

VAN LIFTS

U

1-800-THE LIFT

RESPOND

Ventilator Dependence

D.S. (August 1994) wanted to know how other parents caring for a child who is ventilator-dependent "deal with everyday life." D.S. is the parent of a two-and-a-half-year-old who has a form of muscular dystrophy.

As a result of congenital cytomegalovirus (CMV) infection, our seven-year-old daughter, Jennifer, has been ventilator-dependent since birth. The number of children like ours is increasing, but I suspect that all parents like us have felt isolated and desperate at those times when even a trip to the grocery store becomes impossible.

Over the years, there have been important elements that have helped our family. First, you need to have a reliable respiratory care company, a good relationship with a hospital pediatric pulmonary rehabilitation department and an available physician. These professionals must be people who know what a tremendous responsibility you have and understand the stresses you may feel. They need to be able to teach you how to care for your child and be available to help you troubleshoot technical problems that occur.

Second, you need to train additional family members and friends to take care of your son. Although we may think we can provide 24-hour-a-day vigilance, we must also find time for ourselves. Teaching others about your son's needs may seem difficult, but make it an important goal.

We have had many adventures with Jenny and her vent. Our van was stolen once, along with her spare ventilator. I wasn't worried about the car—it was the vent I wanted back! In retrospect, it seems that patience, perseverance and a sense of humor have allowed all of us to survive.

Whenever I have been ready to give up, I have realized Jenny wasn't giving up, and that has encouraged me. She has become a delightful little girl, ventilator and all!

E.M.A., Colorado

Community Involvement

J.R. (September 1994) has a nine-year-old son with attention deficit hyperactivity disorder (ADHD), auditory processing disorder and secondary autistic tendencies. He recently completed a year of supported inclusion in the second grade. His social life during that year was difficult, though J.R. and her husband did all they could. J.R. wanted suggestions from parents who have been successful in involving their children in their communities.

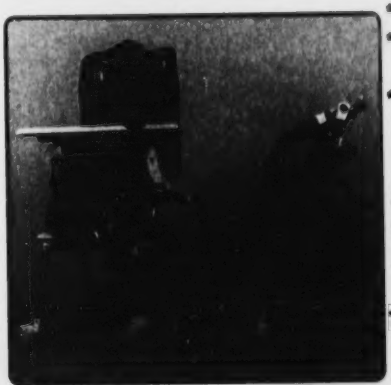
Our 16-year-old son, J.R., was diagnosed with borderline Tourette syndrome, dyslexia and ADHD when he was very young. He had low self-esteem and no self-confidence. He was very shy. Over a nine-year period, he took four different medications. Some helped; others didn't.

Since starting school, J.R. had been in self-contained special classes. The only community involvement we could find was Special Olympics. We tried Cub Scouts, baseball, soccer, basketball and football. None of our efforts were successful.

In 1990, J.R. tried Taekwon-do, the Korean art of self-defense. Within three months, he was off his medication and learning self-control.

Today, J.R. is 6'2", 175 lbs. and a three-time national cham-

Proving good looks, convenience and proper positioning work wonderfully together.



kid-EZ. Adjustable High Chair Base

- Three Models
- Grows from Infant to age 7
- Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
126 Rosebud, #1
Belgrade, Montana
59714

Circle # 47

pion in the sport. He has been a member of the U.S. National Taekwon-do Federation (USNTF) Junior National Team for two years. In April 1995, he will compete in Seoul, Korea to, as he states, "show that 'made in the USA' is better than 'made in Korea.'"

Taekwon-do gave our son self-confidence, higher self-esteem, honesty, self-control and discipline. It also gave him a new meaning in life. I hope you will try it for your son and I hope it works as well for you as it has for us and many other parents who have tried it with kids with ADHD. Don't expect miracles overnight; it will take time, but the rewards are incredible.

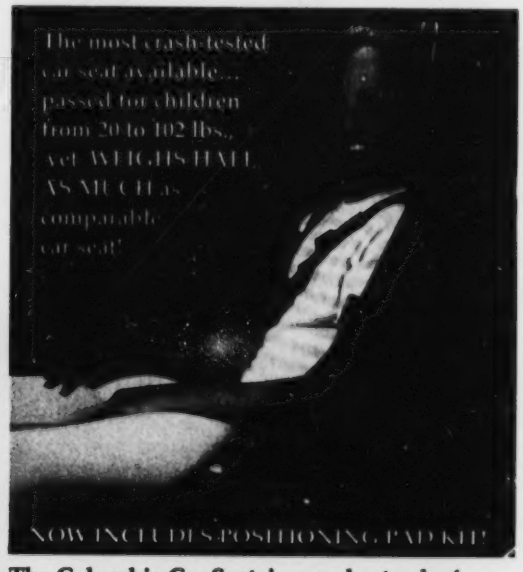
Any reader is welcome to get in touch with me to learn more about Taekwon-do. I have asked *Exceptional Parent* to publish my address. It is: Susan West, 5915 East 25th Place, Tulsa, OK 74114.

Super Light, Super Strong, Super Safe, Super Simple...the Columbia Car Seat has been the #1 choice since 1986 Thousands of Columbia Car Seats are now in use, and we have received some amazing crash stories. One grateful father in Louisiana sent a picture of his badly crumpled van and said, "My 4-year-old son escaped without a scratch, did not even break his glasses." One mother in Colorado wrote, "Thank you for making such a wonderful car seat! I really like how comfortable [my son] is in it. On Dec. 5, 1991, we were hit extremely hard on the passenger side. My 6-year-old son, a healthy 65 pounds, was not hurt at all because your car seat held him so securely."

Our years of *real world* experience give you peace of mind knowing your child is comfortable and secure in our seat!

PLUS it's lightweight, easy to use, good-looking and easy to care for!

Ask for our FREE Full Color Catalog of convenient, helpful products


The most crash-tested car seat available...
passed for children from 20 to 102 lbs.,
yet WEIGHS HALF AS MUCH as comparable car seat!
NOW INCLUDES POSITIONING PAD KIT!

The Columbia Car Seat is your best value!

- The LIGHTEST special car seat–easy to handle!
- Fits easily into ALL vehicles, no matter how compact!
- EXCEEDS all Federal safety standards!
- Approved for car, school bus and even airplane travel!
- Fits your choice of 4 stroller bases!

MEDICAL MFG. CORP. (800) 454-6612 Dept. EL P.O. Box 633 Pacific Palisades, CA 90272

Circle # 11

804

Werdnig-Hoffman Disease

B.O. (September 1994) is the mother of five-year-old Daniel, who has been diagnosed with Werdnig-Hoffman disease (spinal muscular atrophy, type I) and a seizure disorder. He has a feeding tube and has been hospitalized frequently due to aspiration pneumonia. He cannot roll over, sit up, crawl or walk, but uses an electric wheelchair and is very mobile. He retains control of his arms and hands and is exceptionally bright. B.O. wanted to hear from others with information about or experience with this condition.

Like your son, I have spinal muscular atrophy. My 19-year-old sister has it, too. We weren't diagnosed until I was about 19. In 1977, the doctors told our parents that we had Werdnig-Hoffman disease, but they never said what type we had.

My mother says that my sister and I both seemed fine at birth. My sister was doing everything a "normal" child would do until she had her first DPT shot; it seemed to make the disease speed up. I also was fine until I had my first shot. By the time I was 12, I had to get a wheelchair. I was just too weak to hold myself up.

My condition is not as bad as my sister's. I can move around. I can get out of my wheelchair and transfer myself to the couch or bed. But Heather has had to have metal rods put in her back because of scoliosis. She was hospitalized several times when she was younger because of pneumonia. Doctors told my parents that my sister would not live to the age of five. Now, she is almost 20. She is doing great. She graduated from high school and is now attending a local college.

As for me, I'm now 24, married and have two beautiful, "healthy" daughters.

S.C., Tennessee

Undiagnosed

D.T. & B.T. (August 1994) were looking for a diagnosis for their five-year-old daughter, who remains undiagnosed. Katie has hypotonia, microcephaly and mental retardation. She is non-verbal, makes inconsistent eye contact, drools and walks with a wide gait. Her parents thought she

Change Someone's Life. Give Exceptional Parent magazine... the gift that keeps on giving!

12 issues for $18

Special Holiday Rate!

365

EP

12 issues for $18
SPECIAL HOLIDAY RATE!

Gift Cards Will Be Sent!

Gift To:

Name (please print)

Address Apt.

City State Zip

Gift To:

Name (please print)

Address Apt.

City State Zip

From:

Name (please print)

Address Apt.

City State Zip

- ☐ Process my own subscription/renewal at $18 &
- ☐ Process my ___ gift subscription(s) at $18
- My total order equals $_____
- ☐ Payment enclosed (use separate envelope)
- ☐ Bill me

Offer expires December 31, 1994. Canadian Rate $24.00. Foreign Rate $27.00 34M

EP

12 issues for $18
SPECIAL HOLIDAY RATE!

Gift Cards Will Be Sent!

Gift To:

Name (please print)

Address Apt.

City State Zip

Gift To:

Name (please print)

Address Apt.

City State Zip

From:

Name (please print)

Address Apt.

City State Zip

- ☐ Process my own subscription/renewal at $18 &
- ☐ Process my ___ gift subscription(s) at $18
- My total order equals $_____
- ☐ Payment enclosed (use separate envelope)
- ☐ Bill me

Offer expires December 31, 1994. Canadian Rate $24.00. Foreign Rate $27.00 34M

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

Change Someone's Life. Give Exceptional Parent magazine... the gift that keeps on giving!

12 issues for $18

Special Holiday Rate!

806

might have Angelman syndrome but have been told that is not possible.

My daughter, Emily, was diagnosed with Angelman syndrome (AS) when she was three. I was struck by the fact that you were told AS was not a possibility. We were told the same thing.

Emily had all the tests you describe plus an even closer look at the 15th chromosome where most people with AS have a deletion. Our doctor, a geneticist, ruled out AS based on factors I later discovered were erroneous. Most doctors are unfamiliar with or not up-to-date on the syndrome.

On my own, I sent a tape to the Angelman Research Group at the University of Florida. Based on the videotape alone, the doctor there felt an AS diagnosis was likely. A subsequent methalation test showed the chromosomal deletion. We found out that there are labs across the county which can do a DNA probe for AS which provides a better test than even the high resolution g-banding that had been ordered by our doctor. Also, a significant percentage of children are clinically diagnosed with AS, but do not show a deletion. So being "deletion-negative" would not necessarily rule out AS.

Some of the hallmark characteristics of AS which you specifically mentioned in your letter include having a happy disposition, irregular sleep patterns, high level of sociability, hypotonia, petite stature, microcephaly, wide gait, drooling and stronger receptive than expressive language skills. You also mentioned that Katie likes having her hands rubbed. I've never seen that in AS literature, but my daughter is the same way. It relaxes her and helps her fall asleep. Emily also tends to fixate on things she really loves, like water, balloons and "Barney" videos.

I wonder if Katie's inconsistent eye contact might be the result of a vision problem—another common AS characteristic. My daughter, like many people with AS, has strabismus and is nearsighted.

I strongly recommend that you contact the Angelman Syndrome Foundation (5950-77 SW 20th Ave., Gainesville, FL 32607, 904/332-3303) and the Angelman Research Group (University of Florida/Genetics, Box J-296, JHM HC, Gainesville, FL 32610-0296, 904/392-4104). If I had followed my doctor's advice that AS was not a possibility, Emily would still be undiagnosed. I urge you to have your daughter evaluated for AS by those who are the most current on the syndrome.

My husband and I found that one of the most valuable benefits of having a diagnosis is the ability to connect with other families who are facing similar educational and behavioral issues and professionals who are addressing these challenges successfully. Even if Katie is not diagnosed with AS, she has so many AS characteristics that you might benefit from being part of our organization.

M.M., Kentucky

EDITOR'S NOTE: D.T. and B.T. received a number of similar letters from parents whose children were positively diagnosed with Angelman syndrome after the first doctors they had seen had told them it was not a possibility.

Meeting Street Center

Assistive Technology Center

The mission of Meeting Street Assistive Technology Center is to enable people to maximize their independence in school, work, home and community environments through the use of the most appropriate assistive devices available. For more information contact Danielle King at (401) 438-9500 ext. 260 or to make a referral for an evaluation, please contact Kris Auger at (401) 438-9500 ext. 299.

667 Waterman Avenue, East Providence, Rhode Island, 02914
(401) 438-9500 (401) 438-3760 FAX (401) 438-3690 TDD

Meeting Street Center is the local affiliate for the National Easter Seal Society

TEACHING SKILLS TOUCHING HEARTS CHANGING LIVES!

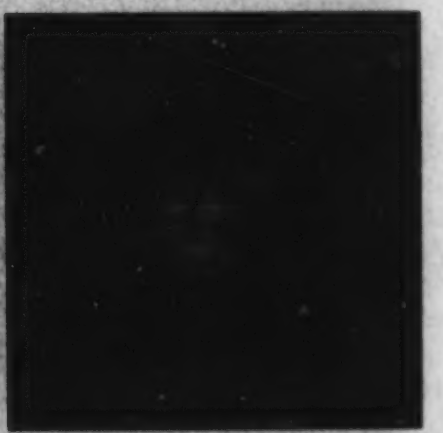
Circle # 268

FAMILIAR FACES

*Four-year-old **Samantha Diaz** shows off her dino-sized charm in a costume she chose herself—"Barney's" friend, Baby Bop. Samantha, who has Down syndrome, was one of the first students with a disability to be included in regular classes at her public school in Yonkers, New York.*

*"Sister" **Mary Chikasuye**, now 13, enjoys trick-or-treating with brother John, 12, in Honolulu, Hawaii. Mary, who has developmental delays, attends Kailua Intermediate School and competes in ramp bowling in the Special Olympics. Mary's family lives on a mountainside overlooking the ocean. They say that getting her wheelchair door-to-door is their favorite Halloween sport.*

*Last Halloween, **Keri Ann Seminaris** was an island princess—Staten Island, New York, that is. Keri, 6, attends P.S. 37. Each year, Keri celebrates her birthday and Halloween within a few weeks—no wonder October is her favorite month!*



*Two-year-old **Corey Graham** rode a devil of a hayride during the Halloween carnival at his early intervention program last year. Corey lives with his parents, Melissa and Jon, in Ovett, Mississippi. He loves going to school, especially when a party is part of the schedule! Corey has developmental delays.*

*This witch casts quite a spell on everyone she meets! **Kerah Moss**, 4, lives in Marietta, Georgia with her parents, Palmer and Marsha, and brother Corey, 13. Kerah, who has cerebral palsy, attends Timberlake Elementary School.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

808

THE ONLY PRESCRIPTION FORMULATION OF LEVOCARNITINE IS NOW AVAILABLE FOR REIMBURSEMENT

- CARNITOR® (levocarnitine) is now available for reimbursement by Medicaid in all 50 states and Medicare in many states.
- CARNITOR® is the only prescription formulation of levocarnitine available and "...should not be confused with dietary and health supplement L-carnitine products.... Such supplements have not undergone review by FDA for safety and effectiveness."[1]
- "Unless these dietary supplements...have been approved...recommendations/ requirements by State Medicaid agencies would be inappropriate for the treatment of systemic carnitine deficiency."[2]
- **"The data from this and previous studies indicate a lack of quality control in the manufacturing process of tablets and capsules in products sold as food supplements, resulting in gross inconsistencies in the properties of the tablets to disintegrate under physiological conditions within a reasonable time. Furthermore, there is evidence that many of the products contain significantly less than the stated amount of the active substance, suggesting also a lack of quality control in the formulation of the product."**[3]
- **"Only the prescription form of levocarnitine is indicated for the treatment of carnitine deficiency. Over-the-counter and health food store products should never be substituted."**[4]

CARNITOR®
(LEVOCARNITINE)

**The Only Prescription Formulation!
Available in Tablets, Oral Solution,
and Ampoules for Intravenous Use...
And *Now Available for Reimbursement!***

Please see full prescribing information on adjacent page.

809

Circle # 269

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

CARNITOR®
(LEVOCARNITINE)

The Only Prescription Formulation! Available in Tablets, Oral Solution, and Ampoules for Intravenous Use... And *Now Available for Reimbursement!*

References: 1. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written communication from the Food and Drug Administration. 2. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written Communication from the Department of Health and Human Services. 3. American Medical Association. Therapy for inborn errors of metabolism. *Drug Evaluations*. Spring 1992: 8:I-8:5. 4. Millington DS, Dubay G. Dietary supplement L-carnitine: analysis of different brands to determine bioavailability and content. *Clin Research & Reg Affairs*. 1993;10(2):71-80.

CARNITOR® (LEVOCARNITINE) Tablets and Oral Solution
For oral use only. Not for parenteral use.

CARNITOR® (Levocarnitine) Tablets (330 mg)
CARNITOR® (Levocarnitine) Oral Solution
(1 g per 10 mL multidose)

CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency.
Tablets and Oral Solution are also indicated for the acute and chronic treatment of patients with an inborn error of metabolism which results in a secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS

General CARNITOR® Oral Solution is for oral/internal use only. **Not for parenteral use**. Gastrointestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3-4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests have been performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* that do not indicate that CARNITOR® is mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or whether to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion

Reference: Rebouce CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D, L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D, L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® Tablets: Recommended adult dosage is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution.
Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED CARNITOR® Tablets are supplied as 330 mg, individually foil-wrapped tablets in boxes of 90. Store at room temperature (25°C/77°F). CARNITOR® Oral Solution is supplied in 118 ml (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection
For Intravenous Use Only

CARNITOR® (Levocarnitine) Injection 1 g per 5 mL
CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS
Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion
Reference: Rebouche CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology.

OVERDOSAGE There have been no reports of toxicity from levocarnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea.

DOSAGE AND ADMINISTRATION
CARNITOR® Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter), and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

HOW SUPPLIED CARNITOR® (Levocarnitine) Injection, 1 gram per 5 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton.

Store ampoules at room temperature (25°C/77°F) in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

STDLN7286/94

810

© 1994, SIGMA-TAU Pharmaceuticals, Inc.

ASK THE DOCTOR

by David Hirsch, M.D.

"Flu" and "Pneumonia" Vaccines

Q My three-year-old has spastic diplegia (a form of cerebral palsy involving two extremities, usually the legs) and mild developmental delays in motor and speech. She is in a preschool program where she gets speech and physical therapy. She has been fairly healthy, usually getting only a few colds each year. The rest of the family is healthy also. Should she get a "flu" shot?

A Your daughter does not have one of the "classic" indications for an influenza vaccine—age over 65; chronic cardiovascular (heart) or pulmonary (lung) disorders, including asthma; chronic metabolic diseases such as diabetes; any condition or treatment causing immunosuppression or a weakened immune system; kidney disease; conditions which hamper the production of blood; long-term aspirin therapy or residence in a nursing home or long-term care facility. However, I believe she should be vaccinated against influenza.

The vaccine is very safe, only occasionally giving local tenderness and fever. The only true contraindication (reason not to give the vaccine) for the influenza vaccine is an allergy to eggs or egg-containing products. One *cannot* get influenza from the "flu" vaccine. While the vaccine will not protect your daughter from the common cold or other respiratory viruses such as parainfluenza (a virus which causes "croup," colds, pneumonia and bronchitis) or R.S.V. (respiratory syncytial virus, the most common cause of bronchiolitis and viral pneumonia in young children), it will significantly reduce the risk or the severity of an illness that would make her miserable for one to two weeks and cause her to miss school and therapy.

Check with your daughter's doctor about the best type of influenza vaccine for her. You'll need to get her immunized as soon as possible. And because the influenza viruses change from year to year, the influenza vaccine needs to be given each year.

Q Our son has epilepsy which is controlled fairly well with an anticonvulsant. He also has asthma and is on inhalation treatments and occasionally steroids. He gets a "flu" vaccine each year. Do you think he also should get a "pneumonia" vaccine?

A The "pneumonia" vaccine is actually a vaccine that gives protection against a number of strains of a bacteria known as *Streptococcus pneumoniae* (pneumococci). Individuals for whom the "flu" vaccine is recommended—those over 65 years old and those with chronic pulmonary disorders, including asthma; immunosuppressive problems or other chronic medical conditions—should receive this vaccine also. It also is recommended for children over two years old who have chronic illnesses which may cause an increased risk of pneumococcal infection.

Unlike the influenza vaccine, the pneumococcal vaccine usually needs to be given only once. Side effects such as redness and pain at the injection site are common, but typically very mild. Please contact your son's physician for more information about this vaccine.

***Ask the Doctor** is a regular department of EXCEPTIONAL PARENT in which questions from readers are answered by David Hirsch, M.D., a board-certified pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Whenever possible, Dr. Hirsch makes specific suggestions. However, since Dr. Hirsch is responding to letters and will not have personally examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch occasionally mentions specific products or medications, he is doing so to illustrate his suggestions; he is not endorsing any specific products.

*To submit a question to Dr. Hirsch, write or fax: **Ask the Doctor**, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

811

The Alliance for Technology Access presents...

Real People, Real Technology, Real Solutions

The Alliance for Technology Access (ATA) is dedicated to redefining human potential through the imaginative and empowering application of technology for children and adults with disabilities. Now numbering 47 centers in the United States and Canada (see list beginning on page 26), each center provides opportunities for people with disabilities, their families, friends, advocates and service providers to get hands-on experience to learn more about the ways assistive technology can enhance independence, achievement, productivity and quality of life. Working in collaboration with 75 technology developers and manufacturers, each ATA center is equipped with the latest information about available products and services.

Technology is no longer a luxury in our society. Information about and access to technology, including products and information services, has become crucial to educational achievement, employment and participation in the world. Each ATA center is ready and eager to help potential users of technology become familiar with today's exciting technology tools. Through demonstrations, consultations, seminars and a myriad of other activities, more than 100,000 people each year are discovering tools and services which significantly enhance their lives. In these pages, you will meet a few of those people...

Michael

Technology helps to make inclusion work

By Dana Sharpe

When I was asked if I wanted to write a short story about my son, Michael, and his use of assistive technology, I was very excited. I'm thrilled to be able to spread the word about how assistive technology has turned Michael into the independent

PHOTOGRAPH BY DEBORAH SILVER

John

Assistive technology helps one child prove the "experts" wrong

By John Duganne

I was born with cerebral palsy in 1971. My first public school program was a development center for children with severe disabilities. Unlike the other kids, I couldn't control my movements and I couldn't talk. The teachers told my parents I was not learning. The school psychologist tested me and said that I was mentally retarded.

Luckily, my parents didn't believe it. They believed I needed friends and support to be able to do things my body wouldn't allow me to do. My stepfather began building switches and other gadgets, and my mother began to advocate for me to be included in everything with kids my age—school, play groups and church. I left public school and began attending a private alternative school where I was the only kid with a disability.

But I still had trouble learning. After two years, the teachers at the private school suggested I return to public school where there would be special education teachers to help me. But my IQ test followed me; people saw my wheelchair and inability to talk before they saw me. Again, I ended up in a class for students with severe disabilities.

Then I got my first computer. It was 1978, and I was seven years old. This was the beginning of real life for me. There were no adaptive devices at that time, so my family's first invention was to put plastic wrap over the keyboard so I wouldn't drool on it. They taped a pencil into my hand to touch the keys. My family and I saw that the computer could be a learning and communication tool for me. And we have been working at making it perform for me ever since.

John Duganne, 23, recently entered the California Institute for the Arts where he is studying computer animation. The technology John uses on an everyday basis includes a Macintosh Power PC 8100 equipped with a Modenta Headmouse with wireless optical sensor which allows John to control a cursor on the screen with head movements. A version of John's story appeared in the book Computer Resources for People with Disabilities.

---

and empowered young boy he is and will continue to become.

When Michael was born six years ago, he was without oxygen for at least 18 minutes during and after birth. As a result, he does not sit, stand or walk. He has speech problems and has not yet been able to feed himself independently.

When Michael was about 18 months old, his early intervention teacher noticed that although Michael could not use his hands very well, he consistently used his left foot to manipulate objects, especially his favorite books. Michael was introduced to a computer by the time he was two years old.

Michael is the first child with multiple disabilities to be fully included into a regular first grade classroom in our school system. Michael's Intellikeys keyboard has become his tool for completing written work on his personal computer in the classroom. During reading lessons, Michael sits with his classmates at the reading table using an adapted chair.

I cannot imagine that Michael's integration would have been as successful if assistive technology had not given him a way to express his thoughts and ideas. Just the other day, Michael's teacher commented that he has become a real "chatterbox" in class. I don't think she realized how happy that made me feel—not that I want Michael to talk out of turn, but his teacher's comment showed me how many friends he has made at school.

I hate to think about how limited Michael's life would be without all this equipment to help him interact with his peers, family and community. Assistive technology has unlocked my son's intellect. It has allowed him to express himself—not only to me, but to the rest of the world. Assistive technology has already empowered his young body and mind. I can only imagine the possibilities in store for his future.

Beth and Michael Smith.

Michael Smith, 6, is a first-grader at T.A. Lowery Elementary School in Charles Town, West Virginia.

During a 1981 visit to the home of 10-year-old John Duganne, Dusty became fascinated with everything John could do with his Apple computer. (See John's story on page 21.) At that time, control was a big issue for Dusty, because she had Down syndrome and very little control over things in her life. With John's computer, she could push a button and make things happen. Dusty's parents had to drag her home from that first encounter with technology.

Dusty, then six, was attending a regular kindergarten class. Her teachers told her parents that she did not pay attention well and would not stay on task. Dusty's mother knew the trick would be to find a task Dusty *wanted* to stay on.

Through her research, Dusty's mother learned that children with Down syndrome tend to be good visual learners. That clinched it. At Christmas, her parents bought Dusty an Apple computer and some software programs that would be both educational and fun. Dusty learned the keyboard quickly and began to practice counting without being asked.

Dusty's mother had no prior experience with computers or other technology. She did not consider herself "mechanically inclined," but she and Dusty learned together. As a way to get Dusty access to a computer at school, her mother volunteered to teach computer use to other students in Dusty's class. As the students played with the computer, Dusty's teacher began to realize Dusty could be included in computer activities, like everyone else.

The computer was an invaluable tool for Dusty as she moved through the educational system. As a student at her local high school, Dusty used a Macintosh computer with large print, a talking word processor and a word-prediction program. Using these tools, she wrote children's books in her English class, then read these stories to the children in the daycare center where she worked.

Dusty's mother says, "Technology gave Dusty confidence in her ability as a learner. She began to feel good about herself. She has always been able to do the things without the technology that she does with it. But without the computer, her work appears to have been done by a six-year-old. With the computer, it looks as if it were done by a person her age. Before technology, writing was something of a 'Catch-22' situation for Dusty. She would write something and have someone make corrections. Then she would copy the text again—fixing the old mistakes, but often making new ones in the process. With a computer, she can follow the usual writing and editing process—and get it right."

Dusty's mother adds, "Technology is highly motivating, and can bring out the best in a child. As a parent, I think it can help you discover the ways your child learns best because it gives you so many exciting avenues to explore. It's a feel-good thing—fun for the whole family. It's also a good integrator. For us, it attracted kids from around the neighborhood who wanted to come over and play."

Dusty, now 19, attends a transitional program at the College of Marin, a community college in northern California. A version of Dusty's story appeared in the book COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES.

814

ATA Update

by Jacquelyn Brand

In addition to the services offered at each ATA center, some of the Alliance's key national initiatives include:

Universal design

The ATA is working closely with mainstream hardware and software developers to build access into their products. One company in particular, Brøderbund Software—the successful publisher of such well-known educational software as Kid Pix, Print Shop and the Carmen Sandiego games—has approached this topic with concern, interest and heart. The Alliance has been working with Brøderbund to identify key universal design elements. The ATA also tests Brøderbund software products to make sure they are compatible with common assistive technology devices. These results are published each year in Brøderbund's catalog of educational software, making appropriate software selection that much easier for parents and educators.

The ATA is very concerned about the growing gap between technology "haves" and "have-nots."

Creating accessible school computer labs

The ATA is collaborating with the Mattel Foundation and IBM in the implementation of a major national initiative—the Computer Learning Lab Project—which brings IBM Writ-

ing-To-Read labs to elementary schools across the country and around the world. ATA trainers travel to schools that have been selected by the Mattel Foundation to receive these labs, and provide extensive training and follow-up for teachers in the use of a variety of software solutions, adaptations and strategies to allow students with disabilities to be full participants with peers. We have learned that labs can be accessible to all students once teachers become comfortable with the tools at their disposal. Working together, Mattel Foundation, IBM and the ATA are demonstrating that all means *all*.

Accessing Computer Technology in our Neighborhoods (ACTION)

The Alliance has just concluded a three-year pilot project designed to reach out into communities and neighborhoods which have been traditionally underserved by technology. In five communities across the country, ATA centers conducted technology fairs, visited shopping malls, HeadStart programs, churches and other key community locations to introduce people to the possibilities of technology.

While one segment of our society becomes more and more sophisticated in using new technologies, the ATA is very concerned about the growing gap between technology "haves" and "have-nots." The ACTION project was designed to develop and implement strategies for reaching communities which have not yet had opportunities to learn about technology. An outreach manual is currently in development.

Coming soon...

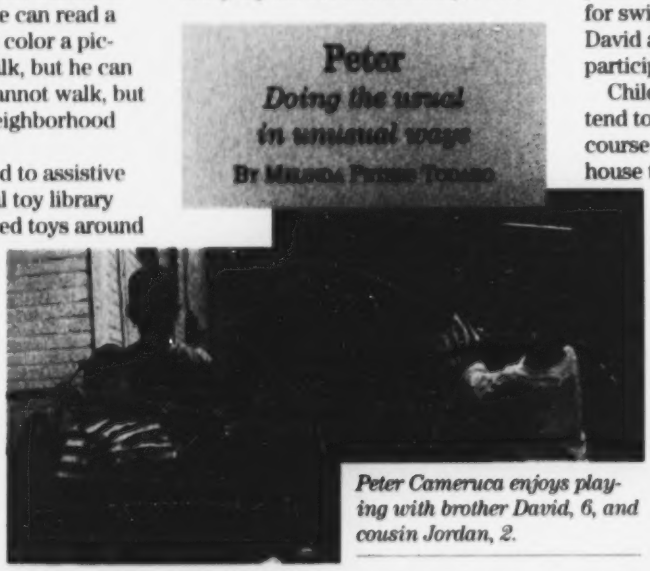
The Alliance is developing a series of seminars on the role of technology in the transition from school to work. Supported by a grant from Citibank and the J.M. Foundation, the ATA will be training students, parents, educators and rehabilitation professionals to look closely at the laws pertaining to transition and the use of technology. The seminars will also focus on technology implementation strategies which may lead to employment.

Jacquelyn Brand is the executive director of the Foundation for Technology Access.

Peter Cameruca is a beautiful four-year-old with cerebral palsy. Peter cannot use his hands, but thanks to assistive technology, he can read a book, play a game and color a picture. He is unable to talk, but he can communicate. Peter cannot walk, but he races around the neighborhood with his friends.

Peter was introduced to assistive technology by the local toy library and began using adapted toys around his first birthday. With toys run by switches, he could play and explore like any other child.

Peter's greatest love is to have someone read to him. His desire to participate in book-reading sessions created his next need for assistive technology. At 18 months, Peter received his first communication device, a Prentke Romich IntroTalker. This first augmentative communication device gave Peter a way to tell the person reading to him when to turn the page and when to read it again. He could also talk about what was happening in the story. By his second birthday, Peter was using augmentative communication to talk to a large number of people about many things.



Peter Cameruca enjoys playing with brother David, 6, and cousin Jordan, 2.

Next, Peter needed a way to participate in activities with his older brother, David, and other children. This created his third need for assistive technology. A Macintosh computer and a variety of games adapted for switch input gave Peter and David an activity in which both could participate on an equal basis.

Children in Peter's neighborhood tend to play in large groups. In the course of a day, kids travel from house to house and yard to yard. Peter's desire to participate created his fourth need for assistive technology. Now, a power wheelchair enables him to be part of the group.

With assistive technology, Peter can go across the street to visit a friend, play games with his brothers and talk about his favorite books with his mom. Assistive technology allows Peter to do the usual in unusual ways.

Peter Cameruca lives in Columbus, Ohio with his parents and two brothers, David and Joey. Melinda Peters Todaro, the author of this piece, is Peter's aunt.

Continued on page 25

You Asked DynaVox To Do Even More...

"I more talk."

"I want to tell a story."

"I want to spell and talk faster."

Now, It Offers 3 Powerful Software Solutions.

DynaVox Was Just The Beginning.

When we first introduced the revolutionary DynaVox® augmentative communication aid, the response was overwhelming.

Because people found that DynaVox's modern dynamic-display system was much easier to learn than traditional devices. So much easier, in fact, that most people could begin using the DynaVox in less than half an hour.

But ease of use is only one part of the DynaVox story. Another, equally important part, is communication *flexibility*.

The Choice is Yours.

Now DynaVox users can choose between 3 powerful software systems, each designed to serve a different range of needs.

DynaSyms® 2000 is the comprehensive language-based system that provides users with nearly two thousand symbols, many of which are electronically animated. But it's not just a collection of pictures, it's a complete, clinically-designed visual language that follows the basic rules of human speech. It helps promote rapid learning and spontaneous self-expression.

DynaWrite® is the software package for those who prefer to spell their messages and employ "word prediction." DynaWrite analyzes as you write, learns your words and offers choices for the next word – based on grammar rules, recency and frequency, a built-in 40,000-word dictionary, and more.

People can then select the word they want with a single keystroke, and compose messages much faster than ordinary letter-by-letter typing.

Finally, **DynaWrite/DynaSyms®** combines all the benefits of both programs into one fully-integrated package. It offers a long-term solution for those who are making the transition to literacy – or who are literate and appreciate the power of symbols.

Dedicated To Communication.

And because the DynaVox is a totally self-contained *communication* device, you get all this capability without having to buy a separate computer and speech synthesizer.

No other single device can offer the complete spectrum of communication – from symbols, written words, and advanced word prediction, to the highest quality synthesized speech. So no other device can offer the value DynaVox can.

A Lasting Commitment.

And that's no accident. It's a direct reflection of our commitment to you. Because we know it takes more than just technology – it takes a thorough understanding of language, and practical, affordable solutions – to keep pace with your growing needs.

So if you know someone who might benefit from DynaVox, give us a call at **1-800-344-1778.** Or see us at the ASHA convention.

SENTIENT SYSTEMS TECHNOLOGY INC.

816

Circle # 65

Zach and Mallory

Regaining independence and control

BY KIM AND GREG HOLLER

For the first few years of their lives, Zach and Mallory Holler could walk, talk, see, hear and play like other children. Then, due to a rare condition called Rosenberg-Chutorian syndrome, each began to lose much of their hearing and vision, as well as the ability to walk and use their arms. Mallory also lost most of her speech when her hearing diminished.

We experienced intense frustration when our children could no longer write their names, color pictures or even talk with friends. But now, thanks to assistive technology, Zach and Mallory are beginning to do things they haven't been able to do for several years.

At a recent assistive technology camp, Zach, now six years old, was able to write his name independently on a touch-window with a home-made head pointer. His beautiful face filled with joy as he said, "I wrote my name all by myself!" At home, he uses an Intellikeys keyboard to play computer games. Soon, he will be using it for spelling and other school-work. His kindergarten teacher plans to incorporate computers into the curriculum so Zach can participate in the same activities as his peers.

Zach Holler

Mallory will soon be four, and her biggest need for technology has been in the area of communication. Fortunately, she has regained some speech and has also found many other ways to communicate with her family. But to help her communicate with the rest of the world, Mallory began using the Liberator, an augmentative communication device. Because of her hearing loss and muscle weakness, it was difficult to find an appropriate method for her to access this device. Now, with a homemade head-pointer like her brother's, Mallory is learning to successfully communicate and play. She also enjoys working on the computer.

Zach and Mallory also have switch-activated toys. We are waiting for several funding sources to come through so we can install switch-activated environmental controls for their use. Assistive technology has given our children some measure of independence, and we know it will continue to play a major role in their futures.

Zach and Mallory Holler live in Dayton, Ohio with their parents, Kim and Greg.

Joshua

Using technology to do the "impossible"

BY HELEN SMALLEY-BOWER

My adopted 13-year-old son, Joshua, has extensive brain damage as a result of accumulated hydrocephalic pressure. Born in Korea with hydrocephalus, Joshua did not receive his first shunt until considerable brain damage had occurred. Because of his problems with long- and short-term memory, most professionals believed his functioning would be extremely limited.

For example, I was told that Joshua would probably never learn math. Frustration mounted as he tried to memorize math facts.

Then, we introduced him to the computer and everything changed. Computer games provided learning opportunities that held Joshua's attention, even with repetition. "Impossible" addition became second-nature. Subtraction followed quickly.

Multiplication brought a return to frustration until we found a software program called *Number Munchers*. Now, Josh knows his multiplication tables perfectly too.

As Joshua's knowledge increases, we face new challenges. We constantly search for computer games that will provide the needed stimulation and excitement to help him continue to advance academically. Reading-comprehension software for older children is a special challenge.

Joshua can read out loud on a sixth-grade level, but his comprehension lags several grade levels behind. So far, we haven't found an exciting reading game for kids his age. But we're still looking!

Economic reality can limit access to technology. In the beginning, we bought several pieces of software that—as we learned only after bringing it home—did not meet Josh's unique needs. We knew we couldn't afford to make this kind of expensive mistake. Fortunately, the software lending library at our local ATA center (ALOHA Special Technology Access Center) has helped to solve the problem. Now, we borrow software programs and try them out at home for two weeks. This way, we can see if they suit Joshua before we make a purchase.

Joshua's progress has already surprised many people. I know that as we continue to find new software and technology suited to his unique needs, Joshua will continue to learn and grow.

Joshua Bower lives in Honolulu, Hawaii with his parents, Helen Smalley-Bower and Scott Bower.

817

Alliance for Technology Access Centers

The Foundation for Technology Access (FTA) began in 1987 as a joint project of a grass-roots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer.

From a small group of parents, consumers and professionals, FTA has grown into one of the nation's largest resources to help adults and children with disabilities gain access to the benefits of adaptive technology.

FTA's most important means of promoting technology access may be its Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals and present workshops on technology use.

Individual centers may also offer additional services. The following pages provide a directory of ATA centers, with a description of the specific services offered by each.

ALABAMA

Birmingham Alliance for Technology Access Center
Birmingham Independent Living Center
206 13th St S
Birmingham, AL 35233-1317
(205) 251-2223 (Voice/TTY)
(205) 251-0605 (FAX)
1, 2, 3, 4, 5, 6, 8, 11, 13, 14, 16, 19, 20, braille services, home visits

Technology Assistance for Special Consumers
PO Box 443
Huntsville, AL 35804
(205) 532-5996 (Voice/TTY)
(205) 532-5994 (FAX)
Internet: tascal@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 19, 20

ALASKA

Alaska Services For Enabling Technology
207 Moller Dr, PO Box 6485
Sitka, AK 99835
(907) 747-7615
Internet: asetseak@aol.com
1, 2, 5, 6, 8, 19, expertise in technology for people with vision impairments

ARIZONA

Technology Access Center of Tucson
4710 E 29th St
PO Box 13178
Tucson, AZ 85732-3178
(602) 745-5588
Internet: tactaz@aol.com
1, 2, 7, 8, 9, 10, 11, 12, 13, 14, 15, 19, 20, disability awareness sessions

ARKANSAS

Technology Resource Center
c/o Arkansas Easter Seal Society
3920 Woodland Heights Rd
Little Rock, AR 72212-2495
(501) 227-3600
(501) 227-3601 (FAX)
Internet: atrce@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, District Assistive Technology Service Plan

CALIFORNIA

Center for Accessible Technology
2547 8th St, 12-A
Berkeley, CA 94710-2572
(510) 841-3224 (Voice/TTY)
(510) 841-7956 (FAX)
Internet: cforat@aol.com
1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 16, 17, 19, 20

Computer Access Center
1807 Wilshire Blvd, #202
Santa Monica, CA 90403
(310) 829-6395
Internet: cacofsmca@aol.com
1, 2, 4, 5, 6, 7, 8, 9, 11, 12, 13, 15, 16, 17, 19, 20

Sacramento Center for Assistive Technology
4370 Mather School Rd
Mather, CA 95655
(916) 361-0553 (Voice/TTY)
(916) 361-0554 (FAX)
Internet: scat1@aol.com
1, 2, 3, 6, 9, 11, 12, 15, 19, 20

Special Awareness Computer Center
Rehabilitation Unit North
2975 N Sycamore Dr
Simi Valley, CA 93065
(805) 582-1881
(805) 582-2855 (FAX)
Internet: sacca@aol.com
1, 2, 12, 13, 15

Special Technology Center
590 Castro St
Mountain View, CA 94041
(415) 961-6789
(415) 961-6775 (FAX)
1, 2, 6, 8, 9, 10, 11, 12, 13, 15, 16, 20

Team of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805-6546
(714) 533-8275
(714) 533-2533 (FAX)
Internet: taskca@aol.com
1, 2, 5, 6, 7, 8, 12, 13, 14, 15, 16, 18, 20, consultations, Saturday open labs

FLORIDA

CITE (Center for Independence Technology and Education)
215 E New Hampshire St
Orlando, FL 32804
(407) 898-2483
(407) 895-5255 (FAX)
Internet: cite@applelink.apple.com
1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, parent support group

GEORGIA

Tech-Able
1140 Ellington Dr
Conyers, GA 30207-4323
(404) 922-6768
(404) 922-6769 (FAX)
Internet: tekablega@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 20, fabrication of adaptive devices and recycling of used medical equipment; information and referral

HAWAII

Aloha Special Technology Access Center
1750 Kalakaua Ave #1008
Honolulu, HI 96826-3725
(808) 955-4464 (Voice/FAX)
Internet: stachi@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 20

ILLINOIS

Northern Illinois Center for Adaptive Technology
3615 Louisiana Rd
Rockford, IL 61108-6195
(815) 229-2163
(815) 229-2120 (FAX)
Internet: ilca@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 17, 18, 19, 20

Technical Aids & Assistance for Persons with Disabilities (TAAD) Center
1950 W Roosevelt
Chicago, IL 60608
(312) 421-3373 (Voice/TTY)
(312) 421-3464 (FAX)
Internet: taadcentr@aol.com
1, 2, 3, 11, 12, 13, 15, 19

INDIANA

Assistive Technology Training and Information Center (ATTIC)
3354 Pine Hill Dr
PO Box 2441
Vincennes, IN 47591
(800) 962-8842 (Voice/TTY)
(812) 882-1128 (FAX)
Internet: inattic1@aol.com
1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 18, 19

KANSAS

Technology Resources and Solutions for People
3023 Canterbury Rd
and 1710 W Schilling Rd
Salina, KS 67401
(913) 827-9383 (Voice/TTY)
(913) 827-0301 (Voice/TTY)
(913) 827-5446 (FAX)
Internet: trspks@aol.com
1, 4, 5, 7, 8, 11, 12, 13, 14, 15, 16, 18

Key to Services

1 Hands-on computer demonstrations
2 Guided exploration and problem-solving
3 Formal technology-needs assessments
4 Assistance in obtaining assistive technology funding
5 Software lending library
6 Loans of computers and hardware
7 Toy lending library
8 Loans of assistive devices
9 Videotape lending library
10 Constructing/adapting switches and devices
11 Technical assistance to IEP teams
12 Teacher training
13 Parent/family training
14 Augmentative communication training
15 Workshops
16 Early childhood/ preschool programs
17 Computer camps/After-school programs
18 Transition training for young adults
19 Technical assistance to employers
20 Newsletter

KENTUCKY

Blue Grass Technology Center
169 N Limestone
Lexington, KY 40507
(606) 255-9951 (Voice/TTY)
(606) 255-0059 (FAX)
Internet: bluegrass@aol.com
1, 2, 3, 4, 6, 7, 8, 9, 10, 11, 12, 14, 15, 18, 19, supported employment services for rural Kentucky

Enabling Technologies of Kentuckiana (enTECH)
Louisville Free Public Library
301 York St
Louisville, KY 40203-2257
(502) 574-1637
(502) 574-1674 (TTY)
(502) 582-2448 (FAX)
Internet: entecky@aol.com
1, 2, 3, 6, 7, 8, 9, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, At-risk Accommodation Project, State/Regional Training Coordinator for Assistive Technology

SpeciaLink
36 W 5th St
Covington, KY 41011
(606) 491-2464 (Voice/FAX)
Internet: spclinkky@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 19, 20, software development, regional center serving SW Ohio, N Kentucky & SE Indiana

LOUISIANA

CATER-Center for Adaptive Technology and Educational Resources
731 Park Ave
Mandeville, LA 70448-4918
(504) 626-7088 (Voice/FAX)
Internet: caterla@aol.com
1, 2, 4, 5, 7, 9, 10, 11, 12, 13, 15, 18, 20

MARYLAND

Learning Independence Through Computers, Inc.
28 E Ostend St
Baltimore, MD 21230
(410) 659-5462
(410) 659-5469 (TTY)
(410) 659-5472 (FAX)
Internet: lincmd@aol.com
1, 2, 5, 10, 12, 13, 15, 17, 19, 20

MASSACHUSETTS

Massachusetts Special Technology Access Center
12 Mudge Way 1-6
Bedford, MA 01730-2138
(617) 275-2446
1, 2, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 19, 20

MICHIGAN

Living & Learning Resource Centre
Physically Impaired Association of Michigan
601 W Maple St
Lansing, MI 48906-5038
(517) 487-0883 (Voice/TTY)
(517) 487-1605 (FAX)
Internet: lircmi@aol.com
1, 2, 3, 5, 6, 8, 9, 11, 12, 13, 14, 15, 19

MINNESOTA

PACER Computer Resource Center
4826 Chicago Ave S
Minneapolis, MN 55417-1098
(612) 827-2966 (Voice/TTY)
(612) 827-3065 (FAX)
Internet: lina100w@wonder.em.cdc.gov
1, 3, 4, 5, 6, 8, 9, 11, 12, 13, 15, 20

MISSOURI

Technology Access Center
12110 Clayton Rd
St Louis, MO 63131-2599
(314) 569-8404
(314) 569-8400 (TTY)
(314) 993-5937 (FAX)
Internet: mostltac@aol.com
1, 4, 5, 6, 9, 12, 13, 15, 19, 20

818

MONTANA

Parents, Let's Unite for Kids
MSU Billings SPED267
1500 N 30th St
Billings, MT 59101-0298
(406) 657-2055 (Voice/TTY)
(406) 657-2061 (FAX)
Internet: plukmt@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, book lending library, MedLine searches, database, Parent Training Center

NEW JERSEY

Center for Enabling Technology
622 Route 10 W, #22B
Whippany, NJ 07981-0272
(201) 428-1455
Internet: cetnj@aol.com
1, 2, 3, 12, 13, 15, 16, 17, 20, open resource times

Computer Center for People with disAbilities (CCdA)
35 Haddon Ave
Shrewsbury, NJ 07702-4007
(908) 747-5310
(908) 747-5936 (FAX)
Internet: ccdanj@aol.com
1, 2, 5, 6, 7, 9, 10, 12, 13, 14, 15, 16, 17, 20, specialty groups: ADD club, Kids Helping Kids, Creative Writing

NEW YORK

Techspress
Resource Center for Independent Living
409 Columbia St
Utica, NY 13502-0210
(315) 797-4642
(315) 797-5837 (TTY)
(315) 797-4747 (FAX)
Internet: bprsny@aol.com
1, 2, 3, 6, 7, 8, 10, 11, 12, 13, 14, 15, 18, 19, 20

NORTH CAROLINA

Carolina Computer Access Center
700 East Second St
Charlotte, NC 28202-2826
(704) 342-3004 (Voice/FAX)
Internet: ccacnc@aol.com
1, 2, 4, 5, 6, 8, 9, 10, 12, 15, 16, 19, 20

NORTH DAKOTA

Pathfinder Services of North Dakota
1600 2nd Ave SW
Minot, ND 58701
(701) 852-9426
(701) 838-9324 (FAX)
Internet: pathfinder@aol.com
1, 5, 7, 9, 11, 12, 13, 14, 15, 16, 18, 20

OHIO

Technology Resource Center
301 Valley St
Dayton, OH 45404-1840
(513) 222-5222
(513) 222-2101 (FAX)
Internet: trcdoh@aol.com
1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20

RHODE ISLAND

TechACCESS Center of Rhode Island
300 Richmond St
Providence, RI 02903-4222
(401) 273-1990 (Voice/TTY)
(401) 831-1131 (FAX)
Internet: accessri@aol.com
1, 2, 11, 12, 13, 14, 15, 16, 17, 20

TENNESSEE

East Tennessee Special Technology Access Center
3525 Emory Rd NW
Powell, TN 37849
(615) 947-2191
(615) 947-2194 (FAX)
Internet: etstactn@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 19, 20

Technology Access Center of Middle Tennessee
2222 Metro Center Blvd, #126
Nashville, TN 37228
(615) 248-6733 (Voice/TTY)
(615) 259-2536 (FAX)
Internet: tactn@aol.com
1, 2, 3, 4, 5, 6, 8, 9, 11, 12, 13, 14, 15, 19, 20

West Tennessee Special Technology Access Resource Center (STAR Center)
60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888
(901) 668-1666 (FAX)
Internet: startn@aol.com
1, 2, 3, 4, 5, 6, 7, 8, 10, 12, 13, 14, 15, 16, 17, 18, 19, 20

UTAH

Computer Center for Citizens with Disabilities
2056 S 1100 E
Salt Lake City, UT 84106
(801) 485-9152 (Voice/TTY)
(801) 485-8675 (FAX)
Internet: cccdut@aol.com
1, 2, 8, 9, 12, 14, 15, 20

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled
74-B & 75 Kronprindsen Gade
Box 1825
St Thomas, USVI 00803
(809) 777-2253
(809) 774-5816 (FAX)
1, 3, 4, 7, 9, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20

VIRGINIA

Tidewater Center for Technology Access
Special Education Annex
Celebration Station
3352 Virginia Beach Blvd, #112
Virginia Beach, VA 23452
(804) 431-4095 (Voice/TTY)
(804) 431-4089 (FAX)
Internet: tcta@aol.com
1, 2, 3, 4, 5, 8, 9, 10, 11, 12, 14, 15, 16, 17

WEST VIRGINIA

Eastern Panhandle Technology Access Center
110 Mordington, PO Box 987
Charles Town, WV 25414
(304) 725-6473 (Voice/TTY/FAX)
Internet: eptac@aol.com
1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20

Project G.L.U.E. (Getting Linked Together for Understanding & Effectiveness)
South Charleston Public Library
312 4th Ave
S Charleston, WV 25303
(304) 342-6501 (Voice/TTY)
Internet: glueata@aol.com
1, 2, 12, 13, 15

CANADA

Alliance Centre for Technology (Peterborough)
360 George St N #202
Peterborough, Ontario K9J7E7
(705) 741-4214 (Voice/TTY)
(705) 741-4581 (FAX)
Internet: alliance@trentu.ca
1, 2, 3, 4, 10, 12, 13, 14, 15, 19, 20

Is Your Communication System Weighing You Down?

Is the size or weight of your augmentative communication device preventing you from taking it to work or school, shopping, church, restaurants or any other place that you would like to go?

Our devices are portable, lightweight and easy to use and can be taken anywhere. They offer text-to-speech as well as the ability to store phrases. Isn't that what you want from your communication device?

Call for our new 1994-1995 Catalog!

Innocomp
INNOVATIVE COMPUTER APPLICATIONS

1-800-382-8622

26210 Emery Road, Suite 302 · Warrensville Heights, Ohio 44128 · 216-464-3636 · Fax 216-464-3638

Circle # 292

Now he has a place for everything like everyone else.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

1-800-4-MYDESC

RHAMDEC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2240
MYDESC is a trademark of Rhamdec, Inc.

Circle # 103

ATA Vendor Member List

AbleNet
1081 Tenth Ave SE
Minneapolis, MN 55414
(800) 322-0956
1, 3, 5, 10

Access Unlimited
3535 Briarpark Dr,
Ste 102
Houston, TX 77042-5235
(713) 781-7441
11

American Thermoform Corporation
2311 Travers Ave
City of Commerce, CA 90040
(213) 723-9021
2

Articulate Systems
600 W Cummings Pk, Ste 4500
Woburn, MA 01801
(800) 443-7077
1

Berkeley Systems
2095 Rose St
Berkeley, CA 94709
(510) 540-5535
7, 11

Blazie Engineering
105 E Jarrettsville Rd
Forest Hill, MD 21050
(410) 893-9333
2, 11

Broderbund Software
500 Redwood Blvd
Novato, CA 94948
(415) 382-4400
8

Claris Corporation
5201 Patrick Henry Dr, C-56
Santa Clara, CA 95052-8168
(408) 987-7000
8

Closing the Gap
PO Box 68
Henderson, MN 56044
(612) 248-3294
11

Compu-Teach
16541 Redmond Way, Ste 137C
Redmond, WA 98052
(800) 448-3224
8

Consultants for Communication Technology
508 Bellevue Ter
Pittsburgh, PA 15202
(412) 761-6062
3, 5, 9, 10

Corporate Facilities
919 N 5th St
Philadelphia, PA 19123
(215) 440-8840
11

Creative Learning
206 Sacramento St, Ste 305
Nevada City, CA 95959
(800) 576-0538
8

Discis Knowledge Research
90 Sheppard Ave E, 7th Fl
Toronto, Ontario M2N 3A1
Canada
(800) 567-4321
8

Don Johnston
1000 N Rand Rd, Bldg 115
PO Box 639
Wauconda, IL 60084-0639
(800) 999-4660
4, 5, 8

DU-IT Control Systems Group
8765 TR 513
Shreve, OH 44676
(216) 567-2001
3, 10

Dunamis
3580 Highway 317, Ste F
Suwanee, GA 30174-2329
(800) 828-2443
5

Echo Speech Corporation
6460 Via Real
Carpinteria, CA 93013
(800) 377-3246
9

Edmark Corporation
6727 185th Ave NE
Redmond, WA 98052
(800) 426-0856
5, 8, 10

Educational Press
PO Box 32382
Baltimore, MD 21208-8382
(410) 633-0730
8

Education TURNKEY Systems
256 N Washington St
Falls Church, VA 22046
(703) 536-2310
11

Gus Communications
PO Box 4362
Blaine, WA 98231-4362
(604) 279-0110
5

Hartley Courseware
3451 Dunckel Rd, Ste 200
Lansing, MI 48911
(517) 394-8500
4, 8

Humanities Software
PO Box 950
Hood River, OR 97031
(800) 245-6737
8

Innocomp
26210 Emery Rd, #302
Warrensville Hts, OH 44128
(800) 382-8622
1, 11 ***See ad on page 27***

IntelliTools
5221 Central Ave, Ste 205
Richmond, CA 94804
(800) 899-6687
4, 5, 10 ***See ad on page 40***

In Touch Systems
11 Westview Rd
Spring Valley, NY 10977
(800) 332-6244
5 ***See ad on page 29***

Key to products

1. Augmentative communication
2. Braille materials
3. Environmental controls
4. Hardware
5. Interface devices
6. Reading machines
7. Screen enlargement
8. Software
9. Speech synthesizers
10. Switches, switch software
11. Other

kidTECH/SoftTouch
3204 Perry Pl
Bakersfield, CA 93306
(805) 873-8744
10

Laureate Learning Systems
110 E Spring St
Winooski, VT 05404
(800) 562-6801
8, 10 ***See ad on page 38***

Lawrence Productions
1800 S 35th St
Galesburg, MI 49053
(800) 421-4157
8

Madenta Communications
9411A 20th Ave
Edmonton, Alberta T6N 1E5
Canada
(800) 661-8406
3, 5, 10, 11

Marblesoft
12301 Central Ave NE
Blaine, MN 55434
(612) 755-1402
8 ***See ad on page 35***

Mayer-Johnson
PO Box 1579
Solana Beach, CA 92075
(619) 550-0084
5, 8, 9

Microsoft Corporation
One Microsoft Way
Redmond, WA 98052-6399
(206) 882-8080
5, 8, 11

Microsystems Software
600 Worcester Rd
Framingham, MA 01701
(800) 828-2600
5, 7, 8, 10

MicroTalk
Clear Creek Dr
Texarkana, TX 75503
(903) 832-3471
2, 11

PEAL Software
PO Box 8188
Calabasas, CA 91372
(818) 883-7849
8

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1984
1, 3, 5, 10, 11 ***See ad on page 44***

Presentation Electronics
4320 Anthony Ct, #1
Rocklin, CA 95677
(800) 576-9281
3

Raised Dot Computing
408 S Baldwin St
Madison, WI 53703
(608) 257-9595
2

Rhamdec/MYDESC Division
476 Ellis St
Mountain View, CA 94043
(800) 469-3372
4, 11 ***See ad on page 28***

RJ Cooper & Associates
24843 Del Prado, #283
Dana Point, CA 92629
(800) 752-6673
5, 10 ***See ad on page 36***

Roger Wagner Publishing
1050 Pioneer Way
El Cajon, CA 92020
(619) 442-0522
8

Skills Bank Corporation
15 Governor's Ct
Baltimore, MD 21244
(410) 265-8855 ext. 286
8

Stone & Associates
7910 Ivanhoe Ave, Ste 319
La Jolla, CA 92037
(800) 733-1263
8

Sunburst Communications
101 Castleton St
Pleasantville, NY 10570
(800) 321-7511
5, 8

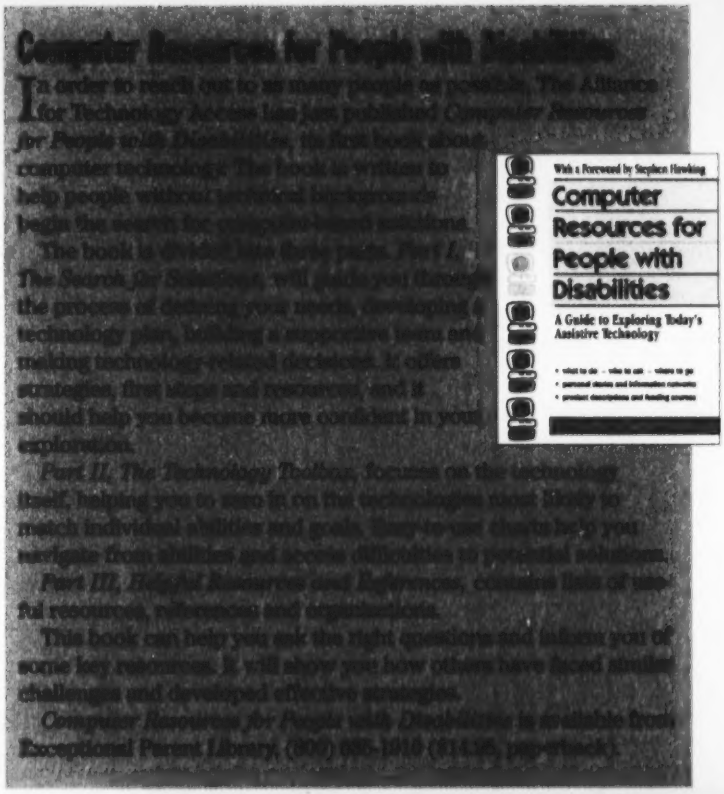
TASH
Unit 1-91 Station St
Ajax, Ontario L1S 3H2
(800) 463-5685
Canada
3, 5, 10, 11

TeleSensory
455 N Bernardo Ave
PO Box 7455
Mountain View, CA 94039
(800) 227-8418
2, 6, 7, 9, 11

WesTest Engineering Corporation
1470 N Main St
Bountiful, UT 84010
(801) 298-7100
5

William K. Bradford Publishing
16 Craig Rd
Acton, MA 01720
(800) 421-2009
8

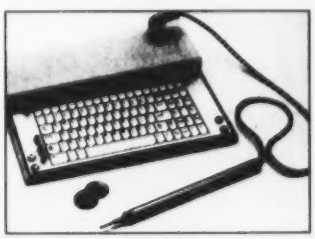
World Communications
245 Tonopah Dr
Fremont, CA 94539
(510) 656-0911
5, 10, 11


With a Foreword by Stephen Hawking
Computer Resources for People with Disabilities
A Guide to Exploring Today's Assistive Technology

The Magic Wand Keyboard

Computer Access that Fits in a Classroom

The Magic Wand Keyboard is a miniature computer keyboard that requires no strength or dexterity. It is used in schools all over the United States and Canada, from kindergarten through college.



The keyboard offers full computer access, including a mouse, to children of any age.

Children with disabilities ranging from MD to neurological disorders to spinal cord injuries can use a computer with the slightest touch of a wand (hand-held or mouthstick).

Your child can use the Magic Wand Keyboard in class, to do homework, write, play games. So can family and friends—because it needs no setup or training. The keyboard works instantly.

30-day money-back guarantee. IBM/Apple Macintosh compatible.

In Touch Systems
11 Westview Road ◆ Spring Valley, NY 10977
800-332-MAGIC

Circle # 286

SPECIAL PRODUCTS FOR SPECIAL PEOPLE

New Expanded Catalog
More Therapeutic And Recreational Products
To Help Everyone Enjoy Success

Gross Motor • Aquatics • Active Play • Manipulatives
Positioning Aids • Adapted Toys/Games/Furniture
Plus SNOEZELEN...sensory stimulation products, introducing KIOSK, an all-in-one new portable package.

Quality Products! Fully Guaranteed!

FLAGHOUSE

150 No. MacQuesten Pkwy., Dept. 96024 Mt. Vernon, NY 10550
CALL TOLL FREE (800) 793-7900
FAX TOLL FREE (800) 793-7922

FREE CATALOG OFFER

Circle # 29

GM MOBILITY℠ PROGRAM

Maintain your daily independence through the General Motors Mobility Program for Persons with Disabilities.

It starts with a toll-free call to our GM Mobility Assistance Center. We'll identify your local driver assessment centers, list your area's installers of adaptive driving devices or vehicle modifications and suggest which GM cars and light-duty trucks might work best for you.

Next, whether you buy or lease a new GM vehicle or dealer demo model, we'll reimburse you for the cost of adapting it–or for the reinstallation of your own adaptive equipment–up to $1000. Qualified customers can finance the cost of the vehicle and any modifications through GMAC in a single transaction at participating dealers.

(Reimbursement for leased vehicle adaptation available only upon lessor's approval to adapt vehicle.)

We're making every day Independence Day.

The people at GM, and GM dealers nationwide, know how important mobility is to your everyday life. Call us today. Or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer and find out how the General Motors Mobility Program can help make every day Independence Day for you.

Call toll-free: 1-800-323-9935
(TDD users: 1-800-TDD-9935)

- **Reimbursement of adaptation costs, up to $1000**
- **Financing available through GMAC**
- **Information on driver assessment centers and adaptive equipment installers**
- **Free resource video, "On The Move Again"**
- **24-hour Roadside Assistance**

General Motors

GUEST EDITORIAL

Too Few Exceptions to the Rule

A vision of true technology access for all

by Bob Williams

One does not have to look far to understand why access to technology is vital. Of course, this access is important to all Americans. But, it is especially important to those of us with significant disabilities. In fact, I would not be writing this piece today if I had not been given access to my very first piece of assistive technology when I was seven years old—some 30 years ago—an IBM electric typewriter.

Years later, I learned that at that time, my teacher did not believe I would ever learn to read. In fact, I am convinced that if had I not been given the typewriter, that teacher's perception would have become a self-fulfilling prophesy. This has happened for many of my contemporaries with cerebral palsy. These people, despite their typical intelligence, face significant difficulties with reading, writing and comprehending the printed word.

Learning is not a passive act. Learning requires a great deal of communication and feedback. Having a typewriter not only enabled me to convince others that I could read; but equally importantly, it enabled me to see that reading and writing had a real purpose and would have real consequences in my life.

Real power

Now that I head a multi-million dollar federal agency, many say I have power. Perhaps so. However, I can tell you that my real power stems not from my position, but from the fact that I have always somehow beaten the odds. I beat the odds by getting a college education—something most Americans with disabilities still have not been able to do. I beat the odds by growing up in a family that helped me to set and achieve some lofty goals. And perhaps most importantly, I have beaten the odds by being able to access the full range of personal assistance and assistive technology I need to live the life that I want to lead.

For me, this includes a great deal of assistance from my wife and best friend, Helen, and others with everyday tasks such as bathing, dressing, eating and managing the paper flow which constantly threatens to overtake my desk. Or the help I receive from my assistance dog, Decoy, in getting up from the floor or walking across a uneven patch of ground. Or the assistance and productivity I demand from my Liberator (an augmentative communication device) and other assistive devices. To me, personal assistance includes any sort of assistance we individuals with disabilities rely on to make our lives more personally and professionally productive.

An exception to the rule

Unfortunately, I am very much an exception to some very important rules in our nation. I say this with little pride, but with a great deal of outrage—outrage that my friend, Vi, went to her grave without ever getting the assistive technology, training or ongoing support she needed to effectively express herself. Outrage that such technology, training and support is still seen as a luxury rather than the necessity it is. And outrage that as a nation, we continue to spend an estimated $240 billion each year to keep people with disabilities needlessly dependent.

I hope you share these feelings of outrage, because your job and mine is not to produce a few more "exceptions." Instead, we need to change the rules of the game.

Dreams deferred

I continue to learn more about assistive technology—about its power, about its potential and most of all, about its dreams deferred. A few years ago, I met a contemporary of mine who also has cerebral palsy, a woman named Kathy. At that time, Kathy was living in Clover Bottom, an institution.

As soon as I met her, Kathy used her communication board to point to the symbols for "I want to go." My wife and I asked the staff what she meant. They replied that Kathy wanted out of Clover Bottom—forever.

I initially talked to Kathy using my manual communication board. Later, as we were leaving, I spoke to her using my Liberator. Kathy made it clear that she was interested in obtaining a similar device. When I told her the law said she should get what she needs, Kathy cried inconsolably, and with good reason.

Kathy is like many others. The greatest crippler she faces is not her disabilities, but others' severe ignorance and profound underestimation of her abilities. Access to supports like personal assistance and assistive technology is critical. In fact, for individuals like Kathy and myself, it's often the only thing that can begin to tear down the walls of myths and stereotypes.

Kathy finally moved out of Clover Bottom and into a group home. It's not perfect, but it's a beginning. However,

although the state obtained a communication device for her some time ago, she has yet to receive any of the support and training she needs to learn how to use it.

Like my friend, Vi, and millions of other Americans with significant disabilities, Kathy seems to have a strange attraction to the proverbial monkey wrench. Or maybe it's just plain inertia—not inertia on Kathy's part, but a lack of urgency and sustained effort by the system.

Where the rubber meets the highway

We all talk a good game about the power and potential of assistive technology. And it is all very true. But—speaking both as an individual and a federal executive—I continu-

America can no longer afford to have only a few of us "exceptions" hanging around.

ally see the need to change the system. That is where the rubber meets the information superhighway. That is where we transform power and potential into everyday realities for real people.

Creating true access to assistive technology means much more than creating access to devices, hardware and software. It means building in training, ongoing support, opportunities for self instruction and troubleshooting. In fact, I have a staff person, Ron, who spends about a third of his time as my technology troubleshooter. This is important because I rely on my Liberator for more than just communication. It is my principal management tool. I use it to access my computer, e-mail and the Internet. And Ron is there to anticipate problems and to solve glitches as soon as they occur. Frankly, I cannot afford to be nonproductive, not even for five minutes or a half hour—certainly not for an entire day.

America can no longer afford nonproductivity either. Those people who are "exceptions to the rule"—like me—are exceptions because we have had access not only to assistive technology, but to the training and ongoing support we need to make it work. And it does not only improve our own lives; it also makes a critical difference in the lives of our families, our communities and our nation. America can no longer afford to have only a few of us "exceptions" hanging around.

Looking toward the future

We need to figure out the best ways to get ongoing technology training, assistance and support to individuals. We must reach out, and reach beyond the traditional ways of responding to the challenges—and opportunities—presented by disability. The disability community must work with those of us in the Clinton Administration to infuse universal access as a pivotal element in the national information infrastructure.

It begins with working with young Americans—those with and without disabilities—especially those who are left out and left behind at the very margins of the American community. It begins with preparing a number of these young men and women to come together to form what might be called a "national personal support infrastructure," offering all individuals with significant disabilities ready access to the same kind of ongoing training, support and troubleshooting that is now available to me.

Access to technology of every sort will increasingly become a prerequisite for learning, working and simply living in twenty-first century America. This will be true for all Americans, but it will be particularly true for Americans with disabilities.

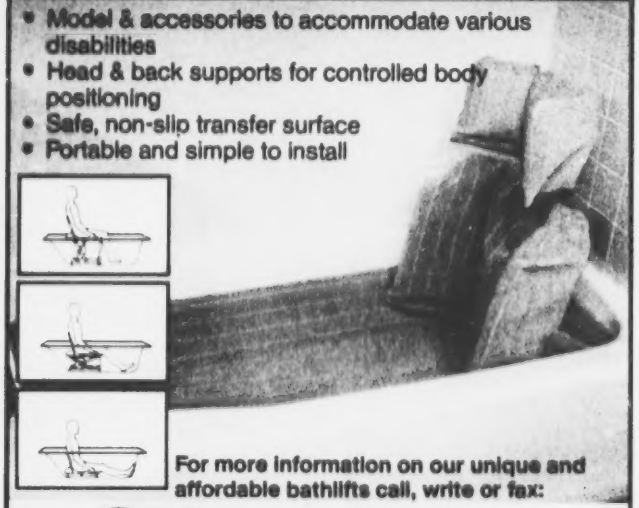
Bob Williams is Commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services. Williams has cerebral palsy and uses augmentative communication. He is well-known for his leadership on disability issues.

Prior to assuming his current position, Williams was a policy associate with the United Cerebral Palsy Associations and served as a co-chair of the Consortium for Citizens with Disabilities Task Force on Personal Assistance Services. A writer and poet, Williams' best-known works are included in his first volume of poetry, IN A STRUGGLING VOICE.

This piece was adapted from a keynote speech given at a July 1994 reception hosted by USA TODAY, IntelliTools, and the Foundation for Technology Access, to celebrate the publication of the Foundation's new book, COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES.

MAKE BATHTIME WITH YOUR CHILD A PLEASURE NOT A CHORE . . .
With an Aquatec Bathlift

- Model & accessories to accommodate various disabilities
- Head & back supports for controlled body positioning
- Safe, non-slip transfer surface
- Portable and simple to install



For more information on our unique and affordable bathlifts call, write or fax:

AQUATEC® The Bathlift Specialists
Health Care Products, L.P.
PIIP-ICM Building • 1003 International Drive
Oakdale, PA 15071-9223
Phone: 412-695-2122 • Fax: 412-695-2922

Circle # 128

824

Disabilities, Opportunities, Internetworking & Technology = DO-IT!

Gaining access to science, engineering and mathematics

by Sheryl Burgstahler

High school sophomore Randy Hammer was a good student who loved to participate in sports. Blind since birth, he was interested in foreign languages and science. However, all printed materials needed to be produced on tape or in Braille or read to him—all slow processes. He wondered if he would be able to keep up with academics if he went to college. Then, Randy became a "scholar" at the DO-IT (Disabilities, Opportunities, Internetworking and Technology) program at the University of Washington (UW) in Seattle.

In this program, Randy gained access to a portable computer system with voice output, a scanner with optical character recognition, a Braille printer and a wealth of human and information resources on the Internet network. Using the Internet, he read a newspaper by himself for the first time in his life. He met engineers, scientists and university students on the net; some of them with similar disabilities. "My computer and access to the Internet have become my eyes to the world," Randy reports.

In live-in summer programs at the university, Randy participated in science and engineering labs and discovered career options. He also had a firsthand taste of dorm life. "I learned what college life is all about and, most importantly, I learned that the early bird catches the shower," Randy says.

Technology opens doors

Only a few years ago, careers in science, engineering and mathematics might have seemed like pipe dreams for individuals with disabilities. However, because of developments in adaptive technologies, more extensive use of computers and networks in these fields and an explosion of electronic resources, opportunities are growing.

Still, challenges remain. DO-IT provides students with the tools needed to face these challenges so they can pursue science, engineering and mathematics programs and careers. Funded primarily by the National Science Foundation, DO-IT began in 1992 in UW's College of Engineering and department of Computing and Communications.

The DO-IT Scholars program allows sophomore or junior high school students with disabilities to study science, engineering and mathematics; experience campus living; develop self-advocacy skills; interact with mentors and use technology to pursue academic interests. The only comprehensive program of its kind in the nation, it admits students from Washington, Oregon, Idaho, Montana, North Dakota and Alaska.

Ben Carroll, who has spinal muscular atrophy, is unable to walk or lift his arms. He uses computers through voice input.

Internetworking

DO-IT scholars learn to use computers and the Internet to explore academic and career interests. Computers and adaptive technologies are selected for each participant; local Internet connections are established and in-home training is provided.

Although Duchenne muscular dystrophy has slowly taken away one scholar's ability to walk, dress himself and manipulate a fork, adaptive technologies have allowed him to interact with hundreds of people on the Internet. "I don't see myself as disabled," he says. "I see myself as playing football and baseball even though I don't... Sometimes when I'm e-mailing somebody, I think of myself as being 'normal.' It kind of puts you on equal footing."

Mentoring

DO-IT scholars use electronic communications and personal meetings to connect with post-secondary students and career "mentors" to facilitate academic, career and personal achievements. Mentors study or work in many fields, including computer programming, post-secondary education, statistics, physics, engineering, computer science, computer consulting and biology. Mentors "provide us with useful contacts in academics, career and personal areas... They help participants find their talents and inter-

825

ests, and confirm their goals," one scholar says.

Experienced scholars learn communication and leadership skills as "peer mentors" for new program participants. A parent reports that her son, a scholar with attention deficit disorder (ADD) and a learning disability has helped another child with ADD "by taking the boy to register for high school and showing him around so he will know where things are on the first day of class."

Summer study

At live-in programs held during two consecutive summers at UW, scholars study science, engineering and math through lectures, labs, computer applications and the Internet network. Subjects include oceanography; heart surgery; chemistry; virtual reality; geophysics; material sciences; civil, mechanical and electrical engineering; mathematics; biology; physics and astronomy. As new scholars spent time getting to know students with disabilities different than their own, many were not sure where they would fit in. "Across disabilities there were some very exciting things to see, where students realized they could complement each other," one instructor recalls.

In a computer lab held during this year's summer session, an observer would see 33 students working:

- A student with no use of his hands types by talking into a headset-mounted microphone.
- A scholar who lost both arms in a farming accident types with a device attached to his one remaining elbow, at 20–25 words per minute.

(Left to right) Ryan Fleming, who has a specific learning disability and attention deficit hyperactivity disorder, works alongside Randy Hammer, who is blind.

- A student with limited speech and no functional use of his hands uses an on-screen keyboard controlled with a foot switch.
- A scholar with a learning disability uses spell-check and screen-enlarging software, along with voice output, to help with her reading and writing.

The mother of one scholar who has a learning disability says the summer program boosted her son's "belief in himself and his abilities... This experience has changed the course of his life."

DO-IT does not end on the last day of the on-campus

Mobile Stander for Kids . . .

Moving in a whole New World

Standard Features Includes

- Adustable body joint supports, abductor.
- Pelvic/lateral support jacket.
- Accommadates leg length discrepancies.
- Adustable footplates for dorsi/plantar flexion.
- Attendant brakes.
- Choice of positioning or activity tray.

Accessories

- Spoke guards, handrims, tote bag.
- Head support for hyper-extension.
- Removable chin cover (drooling)
- Colorful fabrics and space age design make it appear "cool" to kids.

Available in 3 sizes to accommodate children from 2-10 yrs old.

TAYLOR MADE™ HEALTHCARE

10 West 9th Avenue
Gloversville, New York 12078
1-800-258-0942 • Fax: (518) 773-9375

• Call and ask about our free evaluation program •

Circle # 289

Richer Life **FLEXACISER**

PERFECT SOLUTION
- Multiple Sclerosis
- Stroke-Head Injury
- Spinal Injury
- Cerebral Palsy
- Muscular Dystrophy

HELPS ELIMINATE
- Poor Circulation
- Spasticity
- Muscle Atrophy
- Swelling Ankles
- Stiff Joints

High Quality Electric Motor with Speed Control

(800) 869-0862 • (310) 693-6372

Richer Life, 8131 Allport Ave., Santa Fe Springs, CA 90670

Circle # 214

826

program. Back at home, scholars log-on to the Internet to continue their conversations and friendships. "It's kind of like going to summer camp," says one scholar, "but to a certain extent I don't ever have to go home."

Special Projects and Events

Scholars also have opportunities to pursue special projects, including collecting scientific resources, administrating systems, editing the DO-IT newsletter and teaching in the summer program. Scholars as well as other pre-college and college students with disabilities and their families, teachers, counselors and service providers can participate in special events, including the UW Computer Fair booth, presentation and reception; the UW Engineering Open House and the UW Health Sciences Open House. Events attract children with disabilities and their parents who, after meeting DO-IT participants, are encouraged to use technology and to pursue science, engineering and mathematics interests.

Signs of success

It is too early to measure the ultimate impact of the DO-IT project, but evidence has begun to appear in the successes of many DO-IT scholars:

- Four scholars who graduated from high school in 1994 are pursuing college programs in genetics, computer programming, electrical engineering and general studies in preparation for more advanced scientific studies.
- One scholar won a four-year NASA scholarship to attend UW; she became aware of the scholarship program during a DO-IT summer study session.
- One scholar won an award for his essay about the Internet in a national contest sponsored by the National Science Foundation, National Center for Education Statistics and NASA; he was subsequently invited to speak at the Washington State "Governor's Technology Conference."
- One scholar works part-time at Microsoft and in UW's Adaptive Technology Lab.

For the scholars, the most important two words in their vocabulary may be "do it." One scholar with health, mobility and speech impairments says DO-IT gives him the skills "so I can do what I want to do."

DO-IT Resources

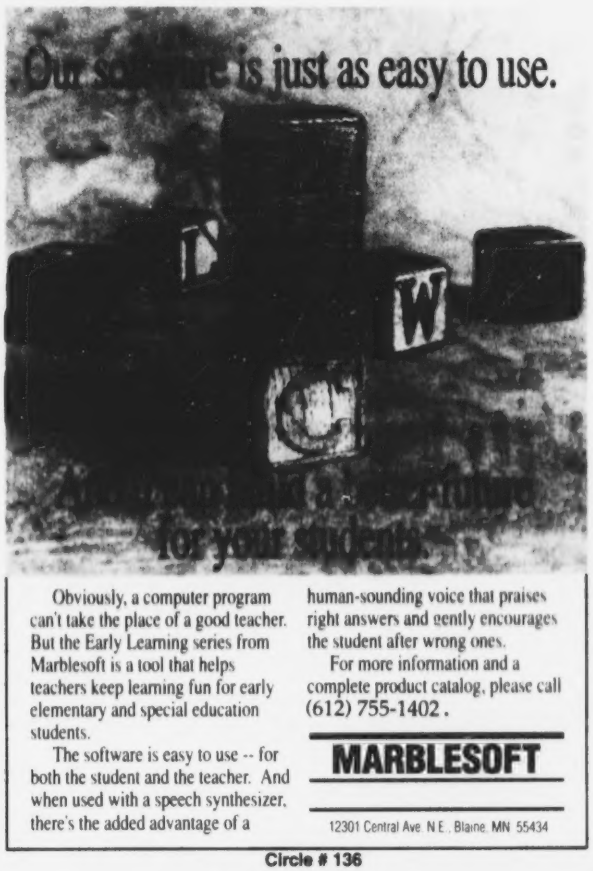
DO-IT has created two videos:

- ***DO-IT Scholars*** follows many of the program participants through 1993's summer session (Free).
- ***Working Together: Faculty and Students with Disabilities*** helps college and university faculty become aware of the academic potential and access needs of students with disabilities ($20, includes written materials).

To obtain either video, or for more information about DO-IT, contact:

DO-IT, University of Washington, JE-25/Room 206, Seattle, WA 98195, (206) 685-3648, (Internet: doit@u.washington.edu).

"I'm so Glad We Found You!"
-Joann Marner
"Thank you, WanderCARE™, for allowing Christopher to live a more "normal" life. I feel our entire family is more relaxed, knowing that Christopher can move and play without getting lost. I'm very glad we found you."
Joann Marner with son Christopher
(age 5, brain injury)
Care Electronics Inc.
• Life-saving Monitoring and Tracking
• Improved Quality of Life for the Whole Family
303-444-CARE
Circle # 138


is just as easy to use.
Obviously, a computer program can't take the place of a good teacher. But the Early Learning series from Marblesoft is a tool that helps teachers keep learning fun for early elementary and special education students.
The software is easy to use -- for both the student and the teacher. And when used with a speech synthesizer, there's the added advantage of a human-sounding voice that praises right answers and gently encourages the student after wrong ones.
For more information and a complete product catalog, please call (612) 755-1402.
MARBLESOFT
12301 Central Ave. N.E., Blaine, MN 55434
Circle # 136

Make your child a star in my CooperCar!

New and Improved!
1) More power
2) Proportional joystick
3) More speeds

Still...

Adaptable to any child, any switch and...

...less than $1000!

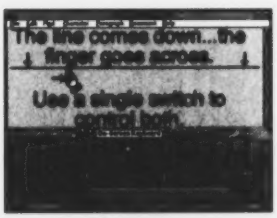
BEWARE! You may see ads with products that look like mine, but they are simply more expensive

Circle # 295

Hi!

I'm RJ Cooper, inventor of the CooperCar, SAM, and many special needs computer programs for your child. I've been helping parents and professionals for 10 years now, and I'm here to help **you!**

When you call me, I'll share with you my experiences, methods, and materials that have helped thousands of children become successful, many for the first time in their lives!



Circle # 296

CrossScanner

...lets one switch (or any pointing device) do *everything* on your Mac or Windows computer!

SAM

...my Switch-Adapted Mouse device...

...lets you plug switches into your computer!

Circle # 297

I also make a variety of special needs software for your Mac, Windows, or Apple II computer.

So, for a free catalog or advice, call me, *RJ*, at...

1-800-RJCooper

RJ Cooper & Associates
24843 Del Prado #283 Dana PT, CA 92629
Voice: 714-240-4853 Fax: 714-240-9785
Email: rjcoop@aol.com

(Left to right) Rodney Lewis, who has arthrogryposis, describes lab visuals to Randy Hammer, who is blind.

Tips for Parents, Schools and Employers

Many small steps taken locally can have a substantial impact and move us closer to a world where people with disabilities have equal access to opportunities in science, engineering and mathematics:

- Give students with disabilities access to computers, electronic communications and network resources at an early age.
- Make facilities, computers, science equipment and programs accessible to people with disabilities.
- Assure that scientific and mathematics publications are available in appropriate alternative formats.
- Encourage students with disabilities to take high school and college math and science classes.
- Establish positive, motivational and lasting interactions between high school and college students with disabilities and engineers and scientists who have disabilities.
- Facilitate transitions to college and employment.
- Help educators and employers appreciate the potential of people with disabilities and create learning and working environments where skills can be developed and productivity can be maximized.

The historical impact of technology on people with disabilities cannot be over-estimated. Computers and networks help them to access resources, communicate with others and perform academic tasks independently. Such tools are required if individuals with disabilities are to compete with their peers without disabilities.

"In the beginning, when they let us work, persons with disabilities were pigeonholed into positions involving basic manual skills such as basket weaving and chair caning; then we got computer smart," says one DO-IT mentor who is blind. "Now we have the information superhighway and we reach out to connect with each other and with the world."

Sheryl Burgstahler is the director of the DO-IT Project. With a Bachelors and Masters degree in mathematics and a Ph.D. in higher education, Burgstahler is an assistant director in the Computing and Communications Department and a research assistant professor at the University of Washington.

828

Robert Walsh

Making the journey to communication with assistive technology

Robert Walsh became a ward of the state as an infant when his birth mother felt unable to care for him because she was unwed and he had cerebral palsy. Unable to communicate, walk or use his hands, Walsh was initially thought to be mentally retarded. After a series of tests when he was four, however, the professionals realized he was probably brighter than average.

Walsh lived in various foster homes and institutions before being adopted at age 11 by Joseph and Catherine Walsh, a couple who had known Bobby since he was very young (their daughter worked and still works at Saint Joseph's Children's Center in Scranton, PA where he was born).

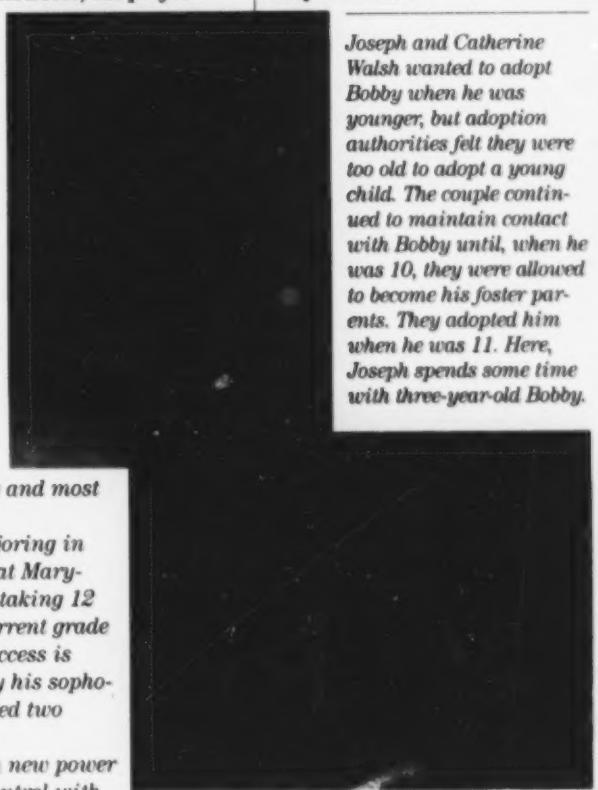
Walsh graduated from West Scranton High School in 1992—and ranked 26th in a class of 197. Not only was he a National Honor Society member, but he was also voted homecoming king and most popular boy in his class.

Now 23, Walsh is a junior majoring in Computer Information Systems at Marywood College in Scranton. While taking 12 credits each semester, Walsh's current grade point average is 3.04. Walsh's success is likely to continue after college; by his sophomore year, he already had received two post-graduation job offers.

Currently, Walsh is enjoying a new power wheelchair which he is able to control with head movements. "The new chair gives me even more mobility and independence," Walsh says. "This I like."

I was born with cerebral palsy. Not being able to talk, walk or use my hands, I felt like a prisoner in my own body. Although the lack of communication was just one of the many disabilities that had overcome my body at birth, it was the most devastating. People do not realize that nearly every minute of our waking lives is spent talking. For the first eight years of my life, I tried very hard to communicate verbally, but I could not speak.

I had to find alternative methods. I tried to communicate with my eyes. Have you ever tried to talk to someone with your eyes? Many times, the people I was trying to communicate with just ignored me; maybe they thought I had a nervous eye condition. People had a hard time understanding what I was trying to tell them—I became very frustrated.



Joseph and Catherine Walsh wanted to adopt Bobby when he was younger, but adoption authorities felt they were too old to adopt a young child. The couple continued to maintain contact with Bobby until, when he was 10, they were allowed to become his foster parents. They adopted him when he was 11. Here, Joseph spends some time with three-year-old Bobby.

Bobby received his first communication board at age 10.

My hands were another problem. I learned to understand sign language by watching others, but this didn't help me because I am unable to use my hands. However, I never gave up on trying to use my eyes. When I wanted to communicate with someone, I would just drive that person crazy with my eye movements until, eventually, they would start asking me questions.

The learning years

When I was 10 and a student at The Home of the Merciful Savior School in Philadelphia, I received my first word board. Finally, the doors of communication began to open. At last, I could ask for a drink or express my feelings. I communicated by shifting my eyes toward a group of numbers that were on the board; each number corresponded to a series of words. Eventually my board became too small because my vocabulary had grown so rapidly.

When I was 11, I was adopted by Joseph and Catherine Walsh. Around this time, I was evaluated for the Express 1, a new augmentative communication device that included synthetic voice output. With all the bureaucracy involved in getting financing for this machine, by the time its purchase was approved, the more advanced Express 3

829

HOLIDAY SPECIAL!

This holiday season, we want your child to benefit from Laureate's award-winning talking software. From now until December 30, 1994, we'll take 25% off any software program you order. We'll even pick up the shipping charges!

25% OFF all Laureate software

This offer applies to individuals only. No school, agency, or institutional purchase orders, please. Orders must be pre-paid by check, MasterCard or VISA. Sorry, but this offer does not apply to hardware and cannot be combined with any other Laureate special.

Call 1-800-562-6801 for a free catalog!

Over 60 talking programs for Apple II, Apple IIGS, IBM, and Macintosh computers.

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

Circle # 48

was about to make its appearance on the market. After a series of articles in a local newspaper, Scranton residents along with the Kiwanis Club bought me the Express 3.

My Express 3 helped me get accepted to the sixth grade at the West Scranton Middle School. After being placed in a "physically handicapped and learning disabled" class, I accomplished six years' worth of learning in one year. My teachers were astounded at what I had accomplished in such a short time.

Full inclusion with technology

A special education supervisor eventually contacted an assistive technology center to set up an evaluation for me. The evaluation team felt I was a good candidate for a Light Talker, another augmentative communication device. One of my teachers received a grant to purchase the device. The school got an Apple computer for me.

With this technology, my learning abilities became unlimited. I was able to enroll at West Scranton High School and was mainstreamed for all my classes. I took French, Latin, algebra and trigonometry.

During my senior year in high school, the local vocational rehabilitation office bought me a Liberator, a highly advanced augmentative communication device which I still use. I access my Liberator with a head pointer—it's like my third hand. When I am not hooked up to my Liberator, I use the head pointer to turn book pages and strike keys on my IBM computer. Technology has also helped

Switch on the Fun

The Scanning 2-XL™ Talking Robot. Innovative, interactive, educational—and fun. Most importantly it is accessible using a single switch through scanning. Developed with the exceptional child in mind, it's the perfect playmate for learning and entertainment. The 2-XL tells stories and jokes, plays your child's favorite audio cassettes, asks questions and waits patiently for your child to scan and select the correct answer. A great gift for the holiday season. Order soon, as quantities are limited. Call or fax InvoTek today for a free catalog and pricing.

INVOTEK CORPORATION
700 W. 20th St.
Engineering Research Center
Fayetteville, AR 72701
(fax) 501-575-7446

2-XL™ is a registered trademark of Tiger Electronics.

1-800-576-6661
Providing Independence Through Technology

Circle # 211

830

me in other ways. I have many books on tape, a dictionary in my IBM computer and an encyclopedia set that I can use by logging on to Prodigy, an on-line service.

Entering college

My fears about making the transition from high school to college resulted in many sleepless nights. I applied at and was accepted by four local colleges. I decided on Marywood College in Scranton.

Before starting school, I worried that my disability would interfere with my education. I was concerned I wouldn't be given the same opportunities as other freshmen. But three days after entering Marywood, I realized this was the right place for me. My fears slowly diminished, and I made up my mind that I was going to work to the best of my ability.

My classes were all in the morning so I was able to come home each day and prepare my work for the following day of classes. This helped me keep up with the work and not fall behind. Sister Francella Shaughnessy, my academic advisor, found me a note-taker for each class. I also tape record each lecture.

Taking tests also was an issue, but it has been dealt with fairly and efficiently by my professors. Some professors give me extra time, or in some instances, I take my tests at special times without the rest of the class. Using my Liberator, I take other exams, like true-false or multiple-choice tests, along with the class. These accommoda-

Dancing with the bride: *Bobby was the ringbearer at the 1983 wedding of his adoptive sister, Cathy.*

SCHOLARSHIPS AVAILABLE

Up to five college scholarships are being offered for the fall of 1995 for a four-year period. Each scholarship provides $3,000 per year ($12,000 total) to each student. Only current high school seniors and college freshmen will be considered.

Applicants should be physically challenged, in a wheelchair, and could not attend college without this help.

All young men and women will be considered without regard to race, color, creed, or state of residence. A private interview is **not** required.

We require a 500-word "statement of need" explaining your physical condition, educational background, and financial status. For scholarship application, write to:

"Doc" and Alicia Keim, Chairscholars
Silver Dollar Ranch, No. 38
Odessa, FL 33556
(813) 920-2737

Deadline Jan. 15, 1995

Chairscholars

"Helping physically challenged students in chairs go to college."

831 Circle # 267

Got a computer?
Don't know what to do with it?

We can help.

(Just ask Alexander).

Since 1979, IntelliTools has been helping people use computers by providing intelligent tools for special education, early childhood, elementary education and adults with disabilities.

To receive a free copy of our new 1994-95 Catalog, featuring over 15 new products, call or write:

IntelliTools, Inc.
5221 Central Avenue • Suite 205
Richmond, CA 94804
800 • 899 • 6687
510 • 528 • 2225 FAX

Circle # 291

Bobby Walsh says his head pointer is like a "third hand." He uses the head pointer to access his augmentative communication device, to turn book pages and to strike keys on his computer.

tions give me an opportunity to earn the grades I deserve.

I have an IBM computer at home and at school that I can use with my Liberator. This is important, because this is how I do all my writing. With the IBM, I have more accuracy on tests. If I use the printer on my Liberator, I might accidentally hit the wrong key—once it is printed out, it cannot be corrected.

In my first semester at Marywood, I put my Liberator through a lot of work and learned a great deal in my Writing Skills class. Sister Immaculata Norton had us write in a journal every day. I stored each journal entry in my Liberator, reading it out loud in class like every other student.

In my second semester, I took classes that were required for my major. I really enjoyed my Computer Tools class. Although I thought I already knew all there was to know about computers, I received a rude awakening in this class. I learned WordPerfect, Lotus 1-2-3 and dBASE III+.

One of the requirements in my Principles of Management class was to give a 10-minute speech on any subject. I chose "Disabilities in the Work Force." I gave the speech with my Liberator. My 10 minutes turned into 15. I must have been a great hit because the class gave me a standing ovation.

Attending Marywood College has given me an opportunity to show the world that just because a person has to use augmentative communication,

832

this does not mean he cannot fulfill his dreams.

People with disabilities have to prove to the world that they are human beings and can be productive people in society. The only way a person with a disability can achieve his or her goals is through education. College can help a person with a disability lead a full and productive life. You have to ask yourself, "Do I want to have a decent job in the future and lead an independent life, or not?"

Kids with disabilities should be given a chance in regular classes. It will mean a great deal in their lives. Don't judge people by the way they look. So many times I was discouraged by professionals because I didn't look or act like an average kid. Little did they know that I had a brain—maybe a better brain than the average kid without a disability. I did

On campus: *Bobby Walsh with dad Joe on the campus of Marywood College in Scranton, Pennsylvania.*

get the chance. Thank God, someone listened to me!

Everyone can make a difference in making this a better world. I can do it, and so can every kid with a disability. One of my goals in life is to help people with disabilities. I know the experience of not being able to communicate. But with the help of friends, families, educators and technology, all the doors of communication have been opened for me.

Opening The Door To Success

Throwing items, turning over furniture, pulling hair . . . the list continues. For Adam, summers mean more than hayrack rides and swimming. They mean concentrated training, lifeskills, and measurable gains through Heartspring's new Summer Intensive Behavior Program.

Adam, 10, has autism and during his first few days of this year's summer program at Heartspring, he averaged about 45 acting-out episodes a day. Heartspring staff members developed a plan to interrupt destructive and aggressive behaviors, and to teach Adam more appropriate ways to communicate his needs and frustrations.

They used reinforcers, such as Adam's favorite foods of raisins and apples, and a trip to the local amusement park. A special picture system was developed to help Adam communicate his wants and express his feelings. His program also included around-the-clock extensive behavior management. By the end of the seven weeks, Adam's daily episodes of acting-out had decreased nearly 90 percent.

And what do Adam's parents have to say about the new program? "We were pleased with the growth our son exhibited. Heartspring's new summer program met Adam's needs in a diverse way that no other program we've looked at could."

To learn how this very special program can benefit your child, call us today.

Heartspring's Summer Intensive Behavior Program
1995 Session: June 19 to August 3
Application deadline: March 1, 1995

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699
1-800- 835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

Using Ordinary Toys for Kids with Special Needs

by Joanne and Stephanie Oppenheim

The products on these pages have been used with success by children with special needs. Most are readily available at, or can be ordered through local toy or book stores.

Puzzles, Games & Manipulatives

Elephant Parade *(Tag, $38)*
This cleverly-designed, circular puzzle board spins like a Lazy Susan with big, wooden, colored elephant puzzle pieces to fit in and take out. It's ideal for children who can't reach far, and the big pegs on each puzzle piece make it easier to grasp. There is space under each elephant to hide "treasures" for a child to discover—like crackers, colored plastic chips or smaller toys.
Activity tip: *Create a game in which each player chooses his own color. Spin the puzzle; if your color stops in front of you, you take one of three colored chips hidden under your elephant. The winner is the first to collect all three chips.*

Or mark a die with a different color on each face. Players throw the die, then find the elephant of the same color. If they choose correctly, they get to take a cracker from under that elephant.

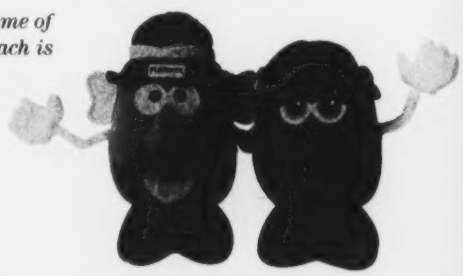
Touch 'N Play Lotto *(Guidecraft, $32)*
Developed with a teacher for children with visual impairments, these four handsome wooden playing boards and matching lotto pieces have raised, textured geometric shapes that give sensory feedback through the fingertips. For extra contrast, put boards against a dark background. This game may develop sorting, matching, counting and language skills.
Activity tip: *For extra fun, put playing pieces in a bag and have players match shapes by feel.*

The playing pieces can also be placed face-down for a concentration-type game. Players turn over two pieces at each turn and feel for matching shapes.

This is the second of two articles adapted from the new 1995 edition of The Best Toys, Books & Videos For Kids *(HarperCollins, $12) by Joanne and Stephanie Oppenheim. The book (available through* Exceptional Parent Library, *800/535-1910) is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens. The 1995 edition includes an expanded chapter on adapting toys for children with special needs; it also includes books and videos of special interest.*

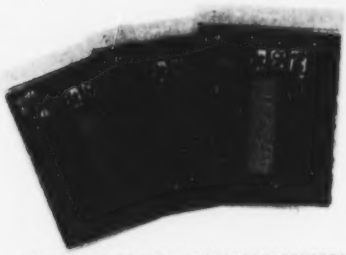
Soft Stuff Potato Head *(Playskool, $13.99)*
For kids who found the traditional peg-in-the-hole Mr. Potato Head hard to use, this all-fabric body with Velcro features is ideal.
Adaptation idea: *Make choices easier for a child with a play board. Glue colored felt on the lid and sides of a sturdy box. Potato Head's features will adhere to the felt. The box can be used to store pieces when the toy is not in use.*

Activity tip: *Try a game of "Name that part" as each is pulled out of a bag and placed on Potato Head's body.*

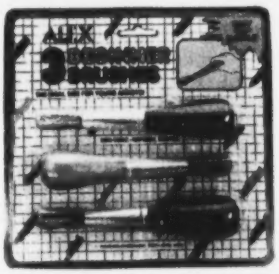


834

Terrific Art Materials



Wax Works *(Chenille Kraft Company, $4.95)*
This is an inexpensive and new modeling material that's not messy! Skinny sticks of colorful wax can be used in a variety of ways. Kids can twist them around pencils, puzzle pieces and other objects. Wax sticks can be shaped into letters and numbers or used to make pretend eyeglasses or sculptures.



Big Handle Paint Brushes *(Alex, $8 for three)*
These extra-large brushes have handles shaped like bulbs. They're perfect for young artists with fine motor difficulties.

Notable Books

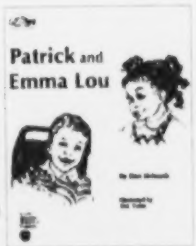
What Happens Next?
by Cheryl Christian
(Checkerboard Press; available only through Exceptional Parent Library, 800/535-1910, $6 incl. shipping and handling.)
This mystery book for toddlers provides visual clues like a picture of a little girl in pajamas with her clothes laid out on the bed. What happens next? Open the flap, and the little girl is dressed. Photos include a child with Down syndrome.

Where's Chimpy?
by Bernice Rabe
photos by Diane Schmidt
(Whitman, $13.95)
Misty, a little girl with Down syndrome, does not want to go to bed without Chimpy, her toy monkey. With help from Dad, she solves the mystery of the lost monkey by recalling the events of the day. A warm, charming story for ages 3–7.

Handsigns
by Kathleen Fain
(Chronicle, $13.95)
A sign-language alphabet book for all ages. Each page shows a familiar creature with an inset drawing of a hand signing the letter featured on each page. Handsome illustrations.

My Buddy
by Audrey Osofsky
illustrations by Ted Rand
(Holt, $14.95)
A school-aged child with muscular dystrophy tells about his special relationship with his service dog, a Golden Retriever named Buddy. Ages 5–10.

Patrick and Emma Lou
by Nan Holcomb
(Turtle Books, $6.95)
Three-year-old Patrick, who has cerebral palsy, is very excited about walking with his brand new walker. But he finds that it isn't quite as easy as it looks! He gets discouraged as he takes a couple of embarrassing tumbles, but his six-year-old friend, Emma Lou, who has spina bifida, helps him to get over his upset feelings. Ages 3–7.



The Oppenheim Toy Portfolio is an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes The Best Toys, Books & Videos For Kids; it also publishes a quarterly newsletter. Both publications include useful sections on adapting products for kids with special needs. These sections are done in conjunction with the National Lekotek Center, a nonprofit organization serving special needs children and their families. For more information, contact the Oppenheim Toy Portfolio, 40 E 9th Street, Suite 14M, New York, NY 10003, (212) 598-0502.

835

We're talkin' now!

Why do the most successful augmentated communicators use PRC communication devices with Minspeak™? Because they enable people to reach their potential. PRC offers devices for virtually every age and ability.

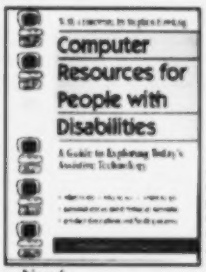
Prentke Romich Company
1022 Heyl Rd. Wooster, OH 44691
800-262-1984 • 216-262-1984 • fax 216-263-4829

Circle # 182

Special Needs Project

SPREADING THE WORD

ABOUT TELECOMMUNICATIONS & ASSISTIVE TECHNOLOGY



Revised 1994 edition
Telecommunication Resources for People with Disabilities.
86 pages. #9960 Spiralbound, $10.95

New!
Computer Resources for People with Disabilities
The Alliance for Technology Access - New!
284 pages. #4116 Paper, $14.95
#4117 Spiral, $19.95 Hardcover, #4118 $24.95

Your one source for good books and information about disabilities

3463 State Street, #282 • Santa Barbara, CA 93105
Orders: Fax/805-683-2341, Voice/800-333-6867
Email/snpbooks@eworld.com

Circle # 288

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle # 26

Kinderwagen products now available through

Taylor Made Healthcare

Bugsy
An ergonomically designed indoor/outdoor postural walker available in 3 sizes. Optional postioning aids, sliding brakes, fixed or swivel wheel frames with color choices of puple or turquoise.

Panda
Postural positioning system available in 3 sizes, fixed or swivel wheel frames, several fabric options and color choices of purple and turquoise. Standard features include tilt-in-space, wheel locks, reversable seat, compact and lightweight. Over 40 options available including locking mobile high chair base.

Flipper
An adjustable bath aid constructed of lightweight tubular steel. Available in 2 sizes with a white frame and blue webbing. Standard features include; wheels and adjustable seat back. Optional head support and chest strap are available.

• **Call and ask about our free evaluation program**

TAYLOR MADE™ HEALTHCARE
10 West 9th Avenue
Gloversville, New York 12078
1-800-258-0942 • Fax: (518) 773-9375

Circle # 290

836

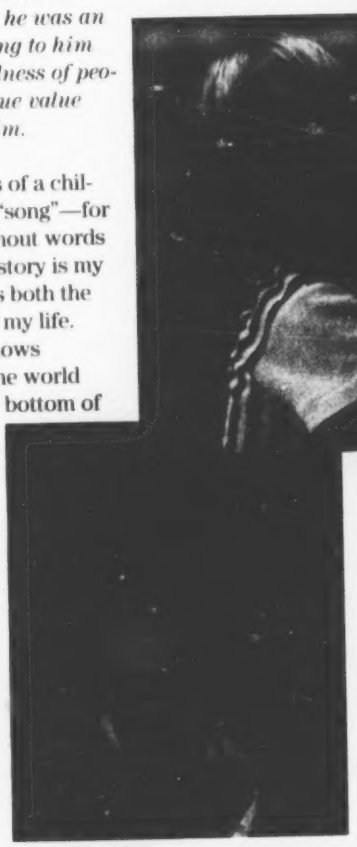
Song of Light

by Susan L. Gengerke

He was no Merlin, no super sorcerer. Ah, no. In fact, it could be said that he wasn't even your average enchanter, though he did not lack ability. He was just a wistful wizard of small-scale spells and minor incantations, content to amuse himself and make his life easy, for he was basically lazy. He remained mostly apart from other magicians and their kind, separated by his furry appearance and thus more at home with other inhabitants of the forest. Yet he was an enchanter of the soul, drawing to him the affection and gentle kindness of people who recognized his unique value and learned to appreciate him.

These were the first words of a children's story—really my first "song"—for my son, Tony, who sings without words and lives in innocence. This story is my second song for Tony, who is both the "darkness" and the "light" of my life.

Anyone who sees Tony knows instantly that he isn't what the world calls "normal." He sits in the bottom of the grocery cart, making discordant and incomprehensible sounds. Sometimes he lets loose with a gleeful, piercing shriek and hugs me so emphatically he nearly pulls me into the cart. At other times, he screams and thrashes so hysterically he has to be removed to the car, which rocks with the intensity of his rage. It is impossible to explain "what's wrong with him" to the casual questioner because Tony has such complex disabilities.



Tony, age 14.

As far as the experts are concerned, he is "multiply handicapped" with a "bleak prognosis." He's been diagnosed as autistic, profoundly retarded and epileptic, with multiple and severe visual, aural, kinesthetic and sensory "deficits." The rest of the world, which likes neat categories, usually accepts the experts' definitions. I am also expected to accept this dismal vision, if I wish to receive the tolerance granted to parents who are "realistic."

An "unrelieved tragedy"

The world has a tendency to view my son's condition as an unrelieved tragedy for both of us. Most people eye us with pity, convinced that Tony's life is irrelevant at best and that mine is wasted in a warped excess of maternal devotion. When I encounter these attitudes, I want to scream, on Tony's behalf, the words of the poster in his room—"See me for what I am, not for what I lack."

But don't mistake me for some quixotic Pollyanna or saint. It's impossible to romanticize the pain and problems our family faces; real life brutally shatters such illusions. The truth is that life with Tony brings a mixture of extreme emotions. It is exhausting to spend years as the primary caregiver for an ever-growing "baby." As you struggle for every step of progress, your body is drained of energy and your spirit is drained of dreams. Yet it is incomparably exhilarating to watch the first steps of this "baby," who had been sentenced by experts to a wheelchair.

Susan Gengerke and Tony, 3.

It is painfully beautiful to be oh-so-gently kissed by this child, who cringed at every touch during the first two years of his life. And after experts told me he would neither understand nor communicate, it is another miracle to hear him say "Mama" with a joyful grin, and to watch him create his own sentences in sign language.

It is incessantly discouraging to have to explain why I love my child, and to justify my faith in him, year after endless year. But more important than the pain is the profound satisfaction of honoring my commitment to someone I love so deeply.

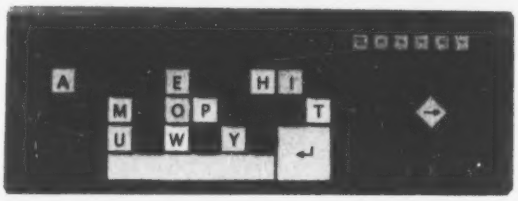
It can be terrifying to try to empathize with him; I know the restrictions and confusions of his life. But how can I do less, as I watch with awe the courage of a child who persistently climbs mountains which I can only imagine?

I can understand, if not accept, the inherent prejudices of society. "Normal" people learn an impressive range of skills and ideas not possible for my son. Tony may never read or write, and he will probably never speak more than a few words. But the unintentionally insensitive arrogance which accompanies *normal* learning assumes that those who lack it are deprived of a real life. Thus, if you cling to the *normal* view of what constitutes a full life, it is an

837

Little Fingers need Big Keys!

..Introducing KID KEYS..
The keyboard for early learners.



KID KEYS is designed with the alphabet and numbers in mind. It makes your computer more user friendly and FUN for the earliest computer users!

- BIG COLORFUL 1 inch alphabet and number ordered keys are easy to find.
- Plug compatible with PC/XT and PC/AT computers. Requires no additional software.
- "Co-Pilot" cable available. Allows simultaneous use of two keyboards. An ideal tutoring tool.

Key Concepts 1-800-293-5090
Box 21066 Charlotte, NC 28277

Circle # 247

Willow River Farms

is an active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

WILLOW RIVER FARMS

For further information contact...
Jimmy R. Haskins, Ed.D.
Director
Willow River Farms
P.O. Box 450
San Felipe, Texas 77473
(409) 885-4121

Operated by: **CRI**
B.R. (Bill) Walker, Ph.D.
Executive Director

Circle # 162

exercise in despair to imagine living an existence like Tony's.

Tony's life may appear to have no depth or value. His future may seem to stretch only towards emptiness. But that view is only blind prejudice. It is emotionally safe to pity Tony. It is difficult, frightening and unsettling to recognize that Tony lives a different life, one which is rich and rewarding in its own way. But the willingness to make that effort is the only way "normal" people can take advantage of the unique opportunity to know Tony—and to learn from him.

Learning from Tony

Tony will never understand Mozart. For one former friend, this was sufficient proof of the devastating emptiness of his life. Yet Tony's pleasure in music is as deep as mine—or hers—while the range of his musical appreciation is uninhibited. Free of intellectual bias, he can delight equally in the music of seagulls, kazoos, crying babies, metal pans *and* Mozart. His "limits" enrich his pleasure in music, while our "superior understanding" limits ours.

Tony can't ride a bike or play softball, but his thorough enjoyment of such overlooked items as doorknobs leads me to wonder just who is deprived! Tony doesn't understand holidays or presents either. But he delights in the paper and ribbons—their color and texture; sometimes even their smell and taste—as much as he enjoys the gift inside. And though the concept of holidays eludes him, he is free of their materialism as well.

Tony, age 19.

Tony has no intellectual or philosophical comprehension of joy. Yet he experiences it abundantly, and in expressing it, shares it exuberantly with those around him. In his gleeful teasing and mischief, he is a funny, exasperating pixie; yet he is honestly without malice. He awards his affection like the prize that it is. His laughter is free, unrestrained and easily contagious.

Tony understands emotions with an instinctive clarity most of us never achieve. He loves without condition or manipulation. He forgives without hesitation and holds no grudges. He accepts each of us without judgment, affirming us as we are—whether or not we accept him.

Tony's "song of light" is a unique and invaluable gift to the world. Those who possess the wisdom to learn from this child receive gifts of lasting insight into what is fundamental, joyful, beautiful and truly important.

Tony, now 23, participates in a home-based program and continues to participate in outside therapies. Susan recently became involved with Partners in Policymaking, a national leadership program which provides advocacy training to families and people with disabilities. Tony and Susan have lived in California and Rhode Island, and currently live on Long Island, New York.

838

Introducing

WEAR•EVER™

THE FREEDOM TO GO WHEREVER YOU WISH℠

Wear Ever Boys: Mild to Moderate Incontinence. 8 oz. capacity.

Wear Ever Missy: Mild to Moderate Incontinence. 8 oz. capacity.

Wear Ever Pull-Up: For Severe Incontinence. 15 oz. capacity.

Introducing WEAR•EVER™. The first family of washable, reusable incontinence underwear that outperforms disposables.

The secret? WEAR•EVER underwear is made exclusively with Hypersorb™, a revolutionary fabric with extraordinary absorbency and quick-drying properties.

In fact, WEAR•EVER underwear holds up to 450cc of urine –15 ounces– without leakage, and that means greater comfort, confidence and freedom.

Plus, WEAR•EVER underwear can be washed up to 200 times without losing its absorptive powers. Which means you'll save at least $1,300* a year over disposables.

WEAR•EVER. All sizes. Lightweight. Fashionable. Environmentally-friendly. And guaranteed for one year or your money back.

To order, or for more information, please call:

1-800-550-4MOM

MasterCard VISA

Wear Ever Butterfly: For Severe Incontinence 15 oz. capacity.

TMI HEALTHCARE PRODUCTS INC.

307 Bacon Road • Rougemont NC 27572 • (919) 477-1387 • Fax (919) 477-2294

• Based on research by TMI.

Circle 939

Back and forth, in and out of conventional hospitals and treatment programs. Because complex behavioral issues frustrate treatment of a young child's neurological deficits. Our unique medical and behavioral approach can break the cycle of multiple failures.

C U M B E R L A N D

Hospital for Children and Adolescents · 9407 Cumberland Road · New Kent, Virginia 23124 · 1-800-368-3472

Circle # 18

More Sibling Concerns

by Donald J. Meyer

This article is an excerpt from SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS *(Paul H. Brookes, 1994). This is the third of four excerpts* EXCEPTIONAL PARENT *will publish. This month's excerpt continues the October excerpt's discussion of some unique concerns of siblings.* SIBSHOPS *is available through* EXCEPTIONAL PARENT LIBRARY, *(800) 535-1910.*

Since the 1980s, we have learned one simple yet far-reaching lesson from the hundreds of parents and siblings we have met, and it is this: Siblings' experiences parallel parents' experiences. Brothers and sisters will encounter joys, concerns and issues regarding the person with special needs that closely correspond to those of their parents. And, although brothers and sisters have the longest-lasting relationship in the family, siblings (as we see again and again) have, compared to their parents, far fewer opportunities to gain access to programs, services and professional support.

Nowhere is this more evident than in the area of peer support. Many parents count on sharing the good times, the not-so-good times and helpful information with a peer who is also the parent of a child with special needs. Some parents connect with other parents through common-sense efforts in programs such as Parent-to-Parent, fathers' programs, or mothers' groups. Many parents maintain informal contact with other parents of children who have similar special needs. For most parents, the thought of "going it alone," without the benefit of knowing another parent in a similar situation, is unthinkable. Yet this happens routinely to brothers and sisters…

Like their parents, brothers and sisters appear to benefit from groups in which they can voice their fears, hopes and doubts. Groups specifically for brothers and sisters demonstrate that somebody cares about the issues facing them and values the important role they play in the family.

…Brothers and sisters, while they have unique concerns, are not the at-risk population once described in the research literature. Like their parents, the vast majority of brothers and sisters of people with special needs do well despite challenges brought about by their siblings' disability or illness. Consequently, programs for brothers and sisters should reflect siblings' and families' strengths while acknowledging their concerns…

Unequal treatment and excessive demands

When we listen to brothers and sisters at Sibshops or during sibling panels, they frequently complain that their siblings "get away with murder." Family rules about behavior, chores, bedtime routines and so forth often do not apply to the child with special needs. Brothers and sisters frequently insist that their sibling *could* comply with many of the family's rules and requirements "if only my parents would make him [or her] do it."

Siblings' views deserve to be heard, even if, as children, they lack a parent's understanding of the "bigger picture." Their alternative perspective—which almost always focuses on what they believe their sibling can do—can provide parents and service providers with fresh insights regarding a child's actual abilities. "My brother never has to unload the dishwasher because he has Down syndrome," one brother told us. "But he can do it. I know he can, because when my parents aren't home, I make him unload the dishwasher…"

ILLUSTRATION BY CARY PHILLO LASSEN

Planning for the future

In families where there is a child with developmental disabilities, frequently there is an assumption—often unspoken—that brothers and sisters will someday become guardians of their sibling. An especially poignant concern for many adult brothers and sisters regards their siblings' future and the role they will play in that future…

When parents fail to involve siblings in planning for the future for the person with the disability, resentment is likely to occur. "My parents won't consider letting Bobby try a group home," one sister told us. "That's all well and good now, but what happens when they die? Will he have to come live with me?"

…It is reasonable to expect that adult siblings of the baby-boom and post-baby-boom generation will be more involved in the lives of the brothers and sisters with disabilities than any previous generation. Unless parents and service providers involve siblings in the planning for their children's future, many adults with disabilities will soon have sibling guardians who are both ill-prepared for the job and resentful of the responsibilities placed on their shoulders…

Increased responsibility

Research suggests some general guidelines for assigning domestic chores to siblings of children with special needs. First, the type of chores assigned should be considered. Are child-care demands resulting in conflict? If so, parents may wish to consider offering siblings a choice in the type of household responsibilities they assume. Par-

841

THE TUNED-IN, TURNED-ON BOOK
About Learning Problems
-Revised Edition-

Help your child learn how to work around learning disabilities

In this best selling self-help guide written directly to adolescents and teens, author Marnell Hayes, Ed.D., takes a positive and practical approach to helping kids capitalize on their individual learning style.

The content of the new edition now includes new study tips, a new glossary, and more 'homework' for parents and teachers to help them understand what a child with learning difficulties needs them to know.

TUNED-IN, TURNED ON BOOK About Learning Problems
6x9" softcover, 163 pp. #090-1 $10.00
PREPAID: Add $2.50 s/h BILLED: Add 10% s/h (min. $2.50)
California residents add sales tax.

ACADEMIC THERAPY PUBLICATIONS
20 COMMERCIAL BLVD. NOVATO, CA 94949-6191
1 (800) 422-7249 Fax: (415) 883-3720

Circle # 244

One size does not fit all!

Children's Specialized Hospital is dedicated exclusively to serving the special needs of children and adolescents.

- Child Study Team
- Learning Disabilities
- Attention Deficit Disorder
- Early Intervention / Pre-School
- Speech and Hearing
- Psychological Services
- Rehab Technology
- Occupational Therapy
- Physical Therapy
- Cognitive Remediation
- Day Hospital
- Recreational Therapy
- Augmentative Communication/ Computer Evaluation
- Nutritional Counseling

Children's Specialized Hospital

MOUNTAINSIDE • FANWOOD • TOMS RIVER
For information in North Jersey call **(908) 233-3720** EXT. **8429** or **8439**
For information in Central and South Jersey call **(908) 914-1100** EXT. **706**

Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation" – the highest distinction awarded by the Joint Commission on Accreditation of Healthcare Organizations.

Circle # 185

ents can offer siblings an opportunity to contribute to the family in other ways—shopping, meal preparation or cleaning.

Second, the amount of demands placed on the typically-developing child should also be considered. Parents should compare their children's level of child-care and household duties with those of their peers in order to determine if their chores are excessive or preventing them from participating in at least some activities outside the home. Responsibility is great, but so is soccer, being in the school play or learning to play the saxophone.

Third, parents should think about which sibling is assuming the care-giving demands. It is not surprising that it is sisters who bear the brunt of the care-giving responsibilities. Brothers are often exempted from demanding care-giving duties. Parents should be encouraged to make sure the chores are spread equitably among brothers and sisters…

Pressure to achieve

The perceived pressure on siblings of people with special needs to excel in academics, sports, music or even behavior has long been noticed by clinicians. Earlier writings suggested that parents placed the pressure on their typically-developing children, as if to compensate for the "failure" of the other child's disability. Whether consciously or unconsciously, parents can pressure their children to compensate for the limitations of the child with a disability, creating resentment and anxiety for typically-developing siblings…

While parents may be the source for some of the pressure siblings experience, it may be that siblings place much of the pressure on themselves… One motivation may be attention. As one sister told us, "Growing up, I did well in school because that was my way of getting attention from my parents." Another brother said he did well in school to counteract the profound sense of loss his parents experienced about his sister's disability. Another sister volunteered that success in academics was her way of demonstrating to the world that it was her sister, not she, who had a disability.

High achievement in academics, sports or behavior may seem like a dubious "concern…" Indeed, the conscientious attitude some siblings have for their schoolwork would suggest that their need to achieve is, in fact, an "unusual opportunity." And it may well be. However, parents should be alert for siblings whose efforts are compulsive or neurotic (like the sibling who cannot be satisfied with a B+ average), or for siblings who are unhappy, despite many successes.

Donald J. Meyer is the director of the Sibling Support Project at Children's Hospital and Medical Center in Seattle, Washington. Don is the younger brother of two siblings who have epilepsy. He is married and the father of four children. His book, SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS, details the program that won the 1992 National Award for Innovation from the Association for the Care of Children's Health.

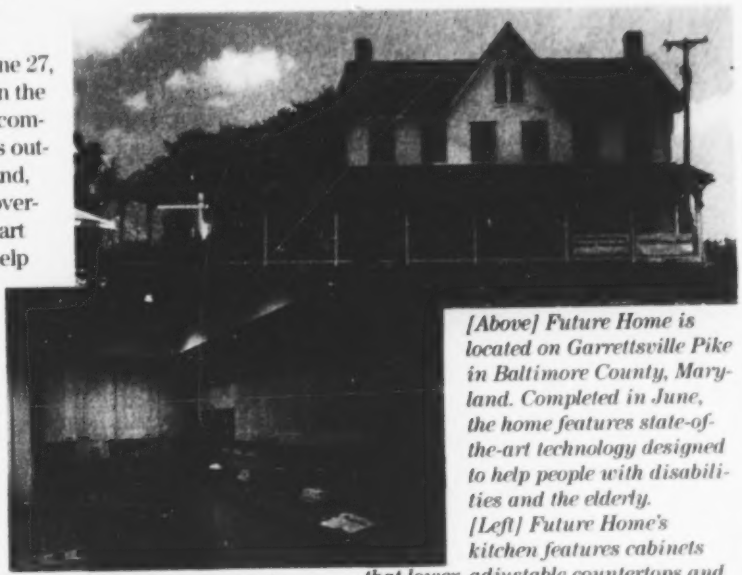
842

Environmental Controls

Future Home provides a model

By Carole Lendosky

During the week of June 27, a project six years in the making was finally completed. Just 16 miles outside of Baltimore, Maryland, Future Home is a home overflowing with state-of-the-art technology designed to help people with disabilities and the elderly. The home was built by the Volunteers for Medical Engineering (VME), a non-profit agency made up of volunteers from the fields of engineering, medicine and rehabilitation.



[Above] Future Home is located on Garrettsville Pike in Baltimore County, Maryland. Completed in June, the home features state-of-the-art technology designed to help people with disabilities and the elderly. [Left] Future Home's kitchen features cabinets that lower, adjustable countertops and an insulated coffee urn that remains touchable even when the coffee is hot.

There are doors that open automatically when a wheelchair approaches, lights that come on when someone enters a room and kitchen cabinets that raise and lower with a flick of a switch. Switches are coded in Braille. Devices can be voice-activated.

Parents of children with disabilities clamored to know how the equipment in Future Home could help them. They wanted to know how much it would cost.

Jeffrey Jerome, Future Home's technology expert, explains, "We see in Future Home how new technology for the home—coupled with barrier-free design— can help children live more independently and help their parents cope with the daily demands of child care. There are many devices that help achieve that end without spending a whole lot of money."

However, Jerome warns against giving a shopping list of prices. "It's all well and good to give a price for the equipment, but proper design for the individual and installation must be considered. A system must be designed based on individual needs and capabilities. And prices can vary depending on the layout of the home."

Future Home's technology

With that in mind, we offer a list of some of Future Home's technology. The list is not at all inclusive. Among the least expensive items are remote controllers and X-10 devices which allow users to turn things on and off without touching a switch.

For $100 or less, a cordless phone can make life easier. Big button switches can be purchased. Keyboard and telephone hands-free positioning arms are also available for under $100. Swing-clear door hinges which won't block any part of the doorway can be used by people in wheelchairs.

For $500 or less, there's a toileting system which acts as a bidet with a drier. You can also buy a voice recognition system for your computer which enables it to respond to verbal commands. Other devices within this price range are keypad door locks, wireless microphones, sensors to open the doors when a wheelchair approaches and a CD-ROM drive with sound card that will allow you to play compact discs and educational software on your computer. Most software packages for children with disabilities are available for less then $500.

For $1,000 or less you can purchase a whole-house telephone/intercom system which allows children to call for help or dial parents at work; a security system that children can work; television cameras to monitor children (with or without sound) or a whole-house infrared system that allows a remote controller from one room to work devices throughout the home. Sinks can be equipped with push buttons on the side of the counter which control the water and prevent scalding.

Less than $3,000 will buy some power doors that can be opened with a hand-held control. Some stairlifts also are obtainable for this price. Automatic lighting which comes on a few seconds after someone enters a room is available. Individual heating and cooling systems for each room are available, as is a wheelchair-accessible shower. Motorized cabinets which are adjustable in height can also cost less than $3,000, as can adjustable countertops which lower to accommodate children in wheelchairs. There are also tables with tops which adjust in height to the proper size of the child as he grows. A small wearable transmitter can monitor the

843

The Disabled Opportunities Center

When a 1986 accident left Tim Connole's 16-year-old stepson, Dominick, a quadriplegic, Connole became determined to provide Dominick with a barrier-free environment.

Connole, a successful building contractor and developer, built a new home, gathering assistive devises and adaptive equipment from around the world. Connole then devoted himself to designing and constructing other homes and facilities for people with disabilities.

Soon, hundreds of people were flocking from across the country to view Connole's home. The attention prompted him to open the Disabled Opportunities Center (DOC) in 1993.

The DOC, in the Kearny Mesa area of San Diego, houses a full-scale model home and model office with equipment from various manufacturers. Visitors can try out devices ranging from a ceiling lift to specialized dishes. A centralized voice-activated computer can open, close and lock doors and windows; turn on the stereo and television and set the alarm system. Cabinets and sinks are height-adjustable with a touch or voice command.

On-site occupational therapists provide individual assessments and training on how to use adaptive equipment. The DOC also offers consultation on the Americans with Disabilities Act (ADA) to help businesses and individuals work in compliance with the law.

For more information, contact Disabled Opportunities Center, 7323 Engineer Road, San Diego, CA 92111, (619) 573-0800 (Voice), (619) 573-1801 (TTY), (619) 573-0886 (fax).

child's voice within a certain distance from the house.

For $10,000 or less, a whole-house home automation system can be purchased. This includes environmental controls which can open power windows and doors automatically. A special security system is available to turn on lights automatically as a child moves through the home.

The benefits of equipping your home with the right devices are numerous: Proper equipment allows parents to monitor the child in other parts of the home, allowing the child to be protected while feeling independent. Depending on a child's ability level, environmental controls can allow him to enter and leave the home independently. Systems can be programmed to keep a child from wandering too far from the house. For parents who work outside the home, there is a system that provides a way of knowing when your child is home. Systems can also be devised to guard against child abuse by caregivers with cameras that record continuously and surreptitiously. There are devices that allow caretakers access to the house only during specific hours.

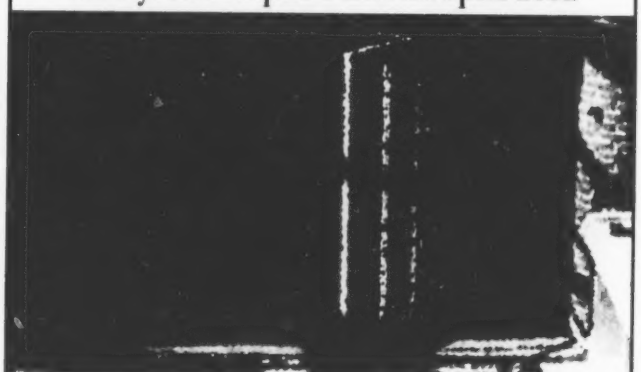
Future Home is open regularly to display these devices and others. For more information about Future Home and how its technology can benefit you, contact VME c/o Montebello Hospital, 2201 Argone Drive, Baltimore, MD 21218, (410) 243-7495.

Carole Lendosky has worked for VME in Public Affairs and Development since 1992.

For people with disabilities,

WE CAN

turn your computer into an open door.



A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3333 (TDD); in Canada, 1-800-465-7999.

At IBM, we can do more than you think.

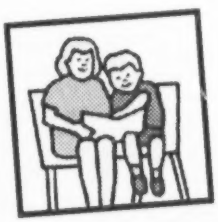
IBM INDEPENDENCE SERIES

© IBM Corp. 1994 ® IBM and Independence Series are registered trademarks of International Business Machines Corporation.

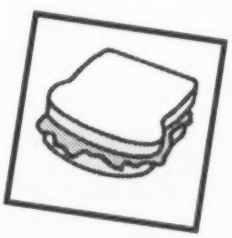
Circle # 121

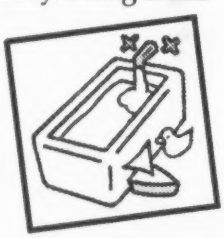
imaginart

Let us help you and your child with friendly, high quality materials:



- picture communication
- feeding and swallowing
- language development *featuring the Hanen Program*
- toys and games to train daily living skills





Pictures shown are communication stickers from our Pick 'n Stick Primary Pack.

Call or write for our free catalog:
Imaginart Communication Products
307 Arizona Street, Dept. EP4, Bisbee, AZ 85603
(800) 828-1376

844

Circle # 41

Dental Care for Children with Disabilities

Common Pediatric Dental Problems

by Steven P. Perlman

Part Four

Though children with some disabilities may be more prone to certain dental problems (see "Special Children are at Greater Risk," August 1994), they must also deal with the more common dental problems of childhood. This article will help parents recognize and obtain appropriate treatment for some common pediatric dental problems:

• **A dark (blackish-bluish) front primary tooth** may indicate a change in the vitality of its nerve, usually due to a past history of trauma to the tooth. Your dentist should be consulted.

• **Facial or gum swelling** most often indicates an abscessed (infected) tooth. This is usually caused by a deep cavity, or occasionally is related to past trauma to the tooth with subsequent nerve damage. In primary teeth, the usual treatment is extraction; in permanent teeth, the normal treatment is tooth pulp therapy, more commonly known as a "root canal." Your dentist should be consulted immediately to help prevent the spread of infection.

• **Cavities,** or dental decay, must be treated in both primary and permanent teeth.

• **An over-retained primary tooth** is a "baby tooth" that is still in position when a permanent tooth is erupting into the same space. The over-retained tooth should be removed immediately, so the permanent tooth can take its rightful position.

This problem occurs most commonly with the lower front teeth, but it can also happen with the upper front teeth. Older children (ages 7–13) may retain primary teeth in the molar and cuspid region. The presence of baby teeth in the middle teenage years indicates a potential problem such as a congenitally absent permanent tooth or an impacted permanent tooth.

• **If a primary tooth is accidentally knocked out of the mouth,** leave the tooth out and seek care immediately. Bring the tooth to show the dentist. If the tooth is intruded (pushed up into the gum) due to an injury, it can often be left to re-erupt, but must be carefully monitored.

• **If a permanent tooth is accidentally knocked out of the mouth,** prompt treatment is essential. The longer the tooth is out of the mouth, the less likely it is that treatment will be successful. Handle the tooth by the top (crown), not the root portion. Try to stick the tooth back into the socket—normally, it will fit quite well—and hold it firmly in place until help is obtained.

If you are unable to replant the tooth in the socket, place it in milk. If milk is not available, have the child hold the tooth in his mouth or place it in water. Do not store the tooth in the child's mouth if there is a possibility he will swallow it.

The dentist will attempt to replant the tooth. The dentist will replace the tooth in the socket and keep it stabile by splinting it to adjacent teeth for several weeks.

• **If primary or permanent teeth are displaced** (knocked to the side but not out of the socket), reposition them as soon as possible and seek professional care immediately.

• **Vague pain in gums** may be caused by canker sores. These are very common in children and can occur in any soft tissue area. Medication can be given to relieve pain. Avoiding hot and spicy foods and drinks will diminish discomfort.

• **Fractured permanent incisors** (front teeth) require prompt treatment. Children with some disabilities are more prone to accidents that can fracture teeth. Seizure disorders and poor motor coordination can lead to falls. If the incisors protrude, they are more likely to be damaged.

Fractured incisors can be restored with a bonding technique or crown. If the nerve is exposed, it will be removed or treated before the bonding treatment is undertaken.

• **Erupting wisdom teeth** (third molars) may sometimes cause pain. An infection called pericoronitis may occur if the tooth does not erupt fully. If this occurs, swelling will occur in the face and/or gums. Immediate care is necessary to prevent the spread of infection.

• **Bruxism,** the grinding or gnashing of teeth, occurs more frequently in children with disabilities. Bruxism usually occurs when the child is sleeping, but some children may also grind their teeth throughout the day. This habit, continued consciously or unconsciously over a period of time, can cause tooth abrasion and loss of tooth structure. In permanent teeth, bruxism can lead to periodontal disease (bone loss) and/or a temporomandibular joint disorder (TMJ) in which the upper and lower jaws are out of alignment resulting in headaches and facial pain. However, most of the time, bruxism will not cause such problems.

Bruxism can be diagnosed at a routine dental visit. Treatment may include bite adjustments or a biteguard appliance. However, treatment is usually not necessary and the habit is outgrown.

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to his private practice, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman is clinical director of the Special Olympics "Special Athletes, Special Smiles" program. He lives in Swampscott, Massachusetts.

845

A scientific breakthrough in dental hygiene

THE AUTOMATIC TOOTHBRUSH

ADA ACCEPTABLE American Dental Association

ORALGIENE 846

The Science of Oral Hygiene

Call toll free to order 1-800-333-ORAL (6725)

VISA, MC, DISCOVER, AMEX, or send check or money order to:
Oralgiene USA, Inc.
421 North Rodeo Drive, Suite 16114
Beverly Hills, CA 90210

CA & NY Residents add 8.25% sales tax.

Circle # 219

A Whole New Ballgame

Reflections on a year of Fathers' Voices

by James May

ALL PHOTOS: GARY SWEET

In *The Fathers' Book*, Harvard professor David Bell remarks, "Despite the things we [men] did learn from our fathers, we usually did not find out how to balance full participation in work and in family. Now we are exploring uncharted territory, with all of the missteps and false starts that such exploration requires."

Fathers of children with special needs understand the discomfort and joys of this exploration better than any other men I know. Daily, they ask themselves hard questions: How do I come to terms with my child's future when it so often seems hopeless and confusing? How do I cope with the feelings of anger and helplessness that continually creep to the surface? How do I help my employer understand the special circumstances of my family without jeopardizing my job? Where do I find enough time in the day to work, to nurture the relationship I have with my spouse and to be a vital part of my child's life?

"Unnatural" Change?

Like many other men, fathers of children with disabilities are making family *the* priority in their lives. Increasing numbers of men are showing up at therapy sessions, doctor's appointments, even circle time. Indeed, the philosophy of family-centered care declares there must be more than one "designated expert" when it comes to the well-being of a child. In *The Nurturing Father*, Yale professor Kyle Pruett captures the essence of these changes when he notes that "the uninvited, uninvolved, unwelcomed, inept father is moving towards obsolescence. But let's not delude ourselves. Such change is frequently unwelcome, highly suspect, and often seen as 'unnatural.'"

But to whom is such change unnatural, and why? Several *Fathers' Voices* pieces have spoken of fathers' ongoing struggles to win recognition for the pivotal roles they play in the lives of their children. In "Fathers Are Caregivers, Too!" (August 1994), Steve Fischer reminds other dads that "we have a long way to go in educating our health care providers about the emotional needs of fathers who have children with disabilities. We fathers must take the lead in educating medical professionals and advocating for ourselves. We must support, encourage and share with each other. We must remind our health care providers that fathers are caregivers, too."

Likewise, Bob Craig, in "I'm Bryan's Dad and Part of His Team" (February 1994), implores men to "stay involved! It's important for you as a parent. It's important for your child with special needs. And it's an important statement to professionals on behalf of all the fathers who will come after you."

A whole new ballgame

Fathers of children with special needs are re-thinking their values and priorities. In doing so, they are discovering that parenting is a whole new ballgame. Bill Abbott ("The Biggest Game," October 1994), an over-the-road truck driver from Columbia, Missouri, dreamed of teaching his then-unborn son to "throw a curve ball and catch a football." After Gregory was diagnosed with cerebral palsy, the game plan changed. Bill wrote, "I have always dreamed of being a coach. Well, I got my wish. Encouraging Gregory to become independent will be the biggest game I will ever coach. Teaching him to stand in one spot without taking a tumble, teaching him to successfully navigate the bathroom, teaching him to pull his pants down *and* back up again—these are much greater rewards than winning any Super Bowl or World Series."

In "The Silent Ringmaster" (November 1993), Robert Greenwald wrote to his son of a wish...

"...to move behind the blueness of your eyes,
to assemble the fragments of sight and sound to make
the animals come alive.
I would rise up like a ringmaster
and crack the whip
that sends the lion roaring
through rings of fire,

847

How Do You Answer Your Telephone If You Have Difficulties??

This Voice-Activated Phone is Your Total Telephone Solution

- Answer by your own voice
- Totally hands-FREE
- Speak from a distance
- Automatically hang up
- Clear speaker phone
- Dial out by using the sip and puff
- No special installation

Order Now by Calling
1-800-647-8887

Available in Black or Beige

TEMASEK TELEPHONE INC.
21 Airport Blvd. #G., So. San Francisco, CA 94080

Circle # 202

Hey Mom, Now There's A Break From the Weather

The *WEATHERBREAKER™*
A COLLAPSIBLE CANOPY FOR WHEELCHAIRS/SCOOTERS

- Protects your child from the rain
- Shades your child from the sun
- Fits all wheelchairs
- Mount it once, then put it on or take it off in a snap

Call your local dealer today!
or order direct
800-795-2392

The *WEATHERBREAKER™* *Base Model $115.00*

When Ordering Include:
1. Manufacturer and model of Wheel Chair/Scooter
2. Choice of teal green, navy blue, cranberry red or charcoal gray
3. Side windows add $20.00, Rear window add $10.00

Checks – Money Orders – Credit Cards Accepted
DIESTCO Manufacturing • P.O. Box 6504 • Chico, CA 95927
Quality Guaranteed • Made in the USA

Circle # 285

or the elephant standing on one hind leg,
or bears—many bears—
dancing in an awkward circle.
All sound! All color! All motion
coming together in mid-brain
with whip-snapping clarity!"

Most fathers, like Bill Abbott and Robert Greenwald, would do anything within their power to bring the world to their children.

Learning from our kids

Many men have written about how a child can become the father's teacher. In "Dreams" (April 1994), John Cox wrote, "All children are a gift to their parents, grandparents, teachers and everyone who comes into contact with them. And they all teach us something that we would not have learned without them. For me, it was to slow down so I could take pleasure in the details of my children's lives. I learned to take an active part in all my children's activities and cherish each of their accomplishments. I am richer for the experience of having a child with a disability. I would not wish it away."

In "What's a Tough Guy to Do?" (June 1994), Thomas Nolan's moving commentary on life with a son who has a life-threatening condition, Nolan notes that the experience of parenting a child with special needs helped him to "become a more caring father for both of my sons. All those 'womanly traits' I was so shocked to find within myself have helped me to

848

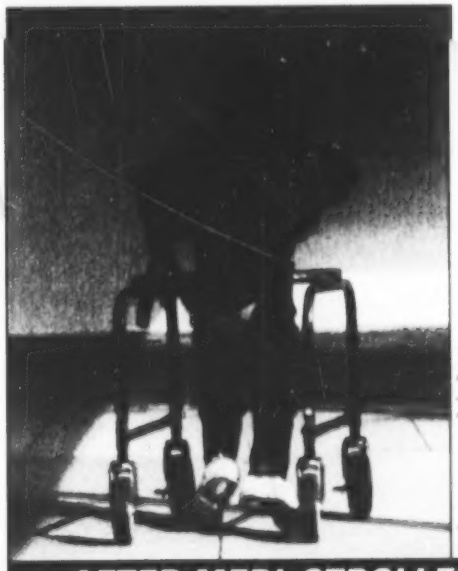
MEDI-STROLLER

Child/Adult Transport System

Breakthrough in Durable Medical Equipment for Children and Adults!
Improve Individual Independence & Mobility

...BEFORE MEDI-STROLLER

Scotty McLaughin's World...



Photography: Bruce Two Eagles

...AFTER MEDI-STROLLER

The *Medi-Stroller* is extremely stable. It is virtually impossible for the individual to fall while experiencing new freedom. People who feel secure are more responsive to therapy. The *Medi-Stroller* allows the person to become more self reliant. Care providers become less likely to suffer from strain and injury, thus reducing the incidence of costly liability and workman's compensation claims.

Simply position the person in the *Medi-Stroller*, adjust to patient's height and realize new found freedom.

The *Medi-Stroller* can also be custom made for specific medical and physical needs.

To place your order just call toll free!

Our representative will answer your questions, take your order and ship your *Medi-Stroller*.

Call Today!
Toll free 1-800-948-5284
(Fax) 1-704-649-9116
Visa, Mastercard Accepted

Optional features include:

- Utility Tray
- Oxygen Bottle Holder
- Privacy Screen
- Bracket for Pulsed Medication System
- Personal Items Bracket
- Bracket for Heart Monitor

We will ship UPS delivering your Medi-Stroller safely and quickly right to your door.

Plus...A 30 day at-home-trial! Buy it and try it for a month. If at that time your are not 100% satisfied return it for a prompt refund of your money!

Native American Indian owned and operated

Circle # 293

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA

Circle # 12

survive the onslaught of emotional and physical demands leukodystrophy has thrust upon me."

Ending the isolation

In this first year of *Fathers' Voices*, I have found myself deeply moved by the willingness of men to communicate their thoughts and feelings. Fathers have written about shattered dreams, anger and fear. But above all else, they have written of their delight in and love for their children.

No one will ever convince me that men don't have strong emotions; they might not always exhibit their emotions for the world to see, but for those inclined to take the time to observe and listen, men's feelings are clear and evident.

I feel blessed in having met these terrific fathers who have been willing to share their stories, passions, strengths, laughter and tears. And I know readers have enjoyed meeting them, too. Many men (and their wives) have written to thank me for lifting the mask of personal isolation, for helping them know that their feelings and emotions are normal and "okay." They speak of finding renewed hope in knowing they are not alone—"Thanks to *Exceptional Parent* and *Fathers' Voices* for the information, support and inspiration."

Men, do continue to send us your reflections on the many meanings of fatherhood. Help us continue to rejoice in the freedom to love, care for and nurture our families. As John Huffacker declares in the *Father Times* newsletter, "The reward for this courageous 'coming out' will be immeasurable for men, women, children and a society that desperately needs this kind of repair within the family."

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

850

Berkshire Meadows...

Young bodies float in a broad expanse of bath-tub warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex, laughter at splashes and water-antics, shared pleasure at accomplishments: reaching out, standing, walking and swimming.

is a private, non-profit year-round residential school for children and adolescents who are severely developmentally delayed and may be multiply disabled.

Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.

This is hydrotherapy at Berkshire Meadows.

These young people experience a variety of benefits from our therapeutic pool. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a moveable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they are unable to walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced, and socialization, independence, and self-esteem fostered.

For the boy in our second picture, the intense relaxation of the Hubbard Tank helps to maintain his range of movement. Kept at a water-temperature of 98 to102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more co-ordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows. Our program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. We have an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's progam.

Gail Charpentier, Exec. Dir.
Berkshire Meadows,
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523

Circle # 6

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle # 27

Home Away From Home

Quality care in a state-of-the-art medically oriented, yet home-like, facility for chronically ill infants, children, and young adults. A one of a kind program staffed by doctors, nurses, therapists, and teachers. If you are thinking about having your loved one cared for outside your home, consider Hacienda de los Angeles with 26 years of experience helping families and their chronically ill family members. Hacienda is located in a semi-rural setting bordered by beautiful South Mountain Park, yet is less than five minutes from the Owens Medical Center.

Hacienda's comprehensive program offers:

- Specialized care for individuals with tracheostomies and those who are ventilator dependent.
- A new facility staffed by professional yet caring employees.
- Open door 24-hour visitation.
- Physician services and round-the-clock nursing care.
- Twenty-four hour respiratory therapy.
- In-house physical, occupational, and speech therapy.
- Nutritional services by a certified nutritionist.
- On-grounds and public school based educational services.
- Private and semi-private rooms.
- Individualized programming designed to allow your family member to reach his/her full potential.
- In-house specialized equipment construction and equipment adaptation.
- Transportation in specially equipped vehicles.

Hacienda de los Angeles, Inc.
In Special Lives, We Make A Difference
1402 East South Mountain, Phoenix, AZ 85040
(602) 243-4231
William J. Timmons, Executive Director

Circle # 199

Annandale Village

Private, 501(c)(3) Nonprofit Community

"THEIR COMMUNITY...WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.

- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.

- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710

Camp Huntington

33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS
A co-ed residential camp for the:

- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

"MAXIMIZING INDIVIDUAL POTENTIAL"
Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.

- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

852

Superior Quality
Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day, residential and vocational programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. **A new community-based program for men has been added.** The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

All Programs Offer These Advantages

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

MARTHA LLOYD COMMUNITY SERVICES

For Information Call

(717) 297-2185

or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947

Circle # 175 853

PRADER WILLI SERVICES

Keystone of Pennsylvania and New Jersey are celebrating 30 years of residential success in programs highlighting community integration and will be expanding services to persons with Prader Willi Syndrome.

- Cost Effective – 24 hour a day program
- Close Medical and Dietary Supervision
- Prescriptive Leisure, Recreational and Behavioral Programming
- Individual and Group Counseling Available
- Well Trained, Caring Staff
- Very Homelike Residences in Poconos of Pennsylvania
- Vocational Training and Day Services for Adults
- Educational Services are Available for Children

Phone **1-800-232-1753**

or write: Keystone City Residence, Inc.
406 N. Washington Ave.
Scranton, PA 18503

Circle # 287

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop

P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
244	Academic Therapy	50
	Apple Computer	40
128	Aquatec Health	32
6	Berkshire Meadows	59
115	Braun Corporation	10
8	Bruno Independent Livings Aids	C3
138	Care Electronics	35
267	Chairscholars Foundation	39
10	Charles C. Thomas	67
185	Children's Specialized Hospital	50
11	Columbia Medical	12
12	Columbia Medical	58
16	Convaid	7
18	Cumberland Hospital	48
19	Devereux Foundation	70
285	Diestco Manufacturing	56
139	Don Johnston	70
25	Equipment Shop	62
26	Estate Planning	44
27	Evergreen Center	60
29	Flaghouse	29
214	Flying Rich Kraft	34
	General Motors	30
199	Hacienda de los Angeles	60
36	Haverich Ortho Sport	6
38	Heartspring	41
39	HMS School	66
121	IBM-Special Needs Systems	52
41	Imaginart	52
286	In Touch Systems	29
211	Invotek	38
292	Innocomp	27
42	Innovative Products	71
291	Intellitools	40
7	J.A. Preston	C4
44	Jay Medical	3
247	Key Concepts	46
287	Keystone City Residence	62
47	Kid-Kart/Kid Care	11
147	Kimberly-Clark	9
48	Laureate Learning	38
136	Marblesoft	35
175	Martha Lloyd	61
293	Medical Transportation Systems	57
268	Meeting Street Center	15
55	New England Villages	68
219	Oralgiene	54
239	Plum Enterprises	5
182	Prentke Romich	44
295–297	R.J. Cooper & Assoc.	36
103	Rhamdec	28
66	Rifton	69
68	Sentient Systems Technology	24
269	Sigma Tau	17, 18
288	Special Needs Project	44
77	Stewart Home School	69
282	Switch Kids	71
289	Taylor Made	34
290	Taylor Made	44
202	Temasek Telephone	56
294	The Communicator	C2
283	Tiger Communications	71
122	TMI	47
215	Tomorrow's Child	6
194	Toys for Special Children	72
85	Voorhees Pediatric Facility	66
162	Willow River Farms	46
86	Woodbury Products	68

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: November 30, 1994

Expiration Date: February 28, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

FREE PRODUCT & SERVICE INFORMATION

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: November 30, 1994

Expiration Date: February 28, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321

Market Place

Bibs

Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

Child Care

Working Solutions
51 E. 42nd Street, Ste. 1511
New York, NY 10017
(212) 922-9562
Agency that specializes in placing professional nannies to work with children who have special needs. NY, NJ & CT

Clothing

Richman Cotton Company
100% Cotton Clothing & Blankets
Easy to dress. Easy to see.
FREE Catalog. 800-992-8924.

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Equipment Dealers

National

American Discount Medical
Save 20% to 30% on Covaid, Carrie Rover, Maclaren & Pogon Strollers. Call 800-877-9100 for FREE BROCHURE.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

Maryland

Choice Seating & Rehab
501 North Centre Street
Cumberland, MD 21502
(800) 327-8713 / (301) 722-6300
Serving Western MD, SW PA, and adjacent WVA. Custom W/C, home & van lifts, electric scooters, PT & OT on staff. Sales and service.

New Jersey

Health Science, Inc.
418 Wall Street, Princeton, NJ 08540
(609) 924-7616 & (800) 841-8923
Authorized Dealer for:
Ablenet • Abovo • Ability Research • Cannon • Franklin • Innocomp • IntelliTools • Mayer-Johnson • MultiVoice by IAT • Tash • Tiger • Toys for Special Children
Take advantage of our loaner, leasing and discount program.

Free Catalogs

Consumer Care Products, Inc.
P.O. Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Lamancha
2625 Brennan Ct.
Plano, TX 75075
(214)867-7757
FACILITATE INCLUSION/Independence. Self-esteem/Language/Motor Skills. Make learning fun, life easier & safer. Call/Write for FREE catalog

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96). Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Summers Laboratories, Inc.
Collegeville, PA 19426
(800) 533-SKIN (7546)
Triple Paste™ for diaper rash and chronic irritation. Used at leading children's hospitals. Available without prescription. Call now for free treatment information.

Category

Nassau Applied Technology Resource Center
Affiliated with the United Cerebral Palsy Assoc. of Nassau County, NY

"On the leading edge of rehab. technology since 1975."

Specializing in:
- Adaptive Seating
- Computer Access
- Augmentative Communication
- Equipment Loan Program
- Product Development & Demo. Center
- Information, referral and many other rehabilitation & technology services.

FREE Service brochure & equipment catalog available on request.

Write to: NATRC, 380 Washington Avenue, Roosevelt, N.Y. 11575 or call 516-378-2000 ext. 263

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Software

Judy Lynn Software
278 Dunhams Corner Rd.
East Brunswick, NJ 08816
(908) 390-8845
IBM PC single switch software. Cognitive age level from 9 months. Programs range from $20-$35. Switch adapter $23. FREE catalog.

UCLA Microcomputer Project
1000 Veteran Avenue/Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
Catalog of dev. appropriate software for children w/disab. 18 mths-5 yrs. Apple, Mac, IBM, cause/effect, game format, basic preschool concepts

BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

Audiotapes

"Little Bits of Rainbow"
12 original songs in the Judy Collins tradition, for parents of children with special needs. By Marianne Kallen. Cassette only, $11.95, P.O. Box 1393, Highland Park, IL 60035

Books for Parents and Professionals

Turtle Books
Provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to Jason & Nordic Publishers, PO Box 441, Hollidaysburg, PA 16648. Call (814) 696-2920 or FAX (814) 696-4250.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free Book Catalog: The 1994 Special-Needs Collection
features a collection of valuable books for parents on Down syndrome, CP, Autism, Tourette syndrome, Mental Retardation, Special Education and more. Woodbine House Contact: 5615 Fishers Lane, Rockville, MD 20852, (800) 843-7323.

Publications

DIRECTIONS: Technology in Special Education.

Comprehensive monthly newsletter assisting parents in the use of computers and technologies for their disabled child. Features adaptive software & hardware reviews, technology tips, the use of multimedia in Special Ed, and information on how to obtain our free DREAMMware® every month.

Published by DREAMMS for Kids, Inc., a non profit, charitable organization. $9.95 annually.

For a free introductory issue contact us at:
2763 Tasha Drive
Clearwater, FL 34621
813-781-7711
or e-mail at
74631.3675@compuserve. com.

Videotapes

Interax Video Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). Interax Training, Inc., PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

To place an ad, contact Barbara Nastro at (201) 680-4874

Put Your Honey in a Gunny

The
GUNNY SACK™
Lap, Leg and Feet Cover
- Fleece lined for warmth
- 100% waterproof

To Order Call
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically complex children ages 6 weeks to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

- An alternative to acute care hospitalization — ***with dramatic cost savings***
- State of the art ventilator unit (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house attending pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available
- Caring for children from the Mid-Atlantic states ***since 1982***

Voorhees Pediatric Facility

Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
(609) 346-3300 • FAX (609) 435-4223
Brochure or video available upon request.

"Accreditation with Commendation"
Joint Commission on Accreditation of Hospital Organizations
Member: National Association of Children's Hospitals and Related Institutions

Circle # 85

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

VAN CONVERSION DEALERS

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Kentucky

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

CHILDREN'S CARE HOSPITAL & SCHOOL

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1000 children with disabilities and their families each year. CCHS offers individualized, family-centered programs through day school, outpatient, outreach, or residential services.

Contact: Nathan Anderson
Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840 or (800) 584-9294

858

CHARLES C THOMAS • PUBLISHER

☐ Hargis, Charles H.—**CURRICULUM BASED ASSESSMENT: A Primer. (2nd Ed.)** '95, 226 pp. (7 × 10), paper.

☐ Phillips, Nancy H.—**CHOOSING SCHOOLS AND CHILD CARE OPTIONS: Answering Parents' Questions.** '94, 112 pp. (7 × 10), 5 il. $31.95.

☐ Lukken, Miriam W.—**READ THIS BOOK BEFORE YOUR CHILD STARTS SCHOOL.** '94, 240 pp. (7 × 10), 5 il., 1 table. $31.95.

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $36.75.

☐ Adamo-Tumminelli, Pat—**A GUIDE TO PEDIATRIC TRACHEOTOMY CARE. (2nd Ed.)** '93, 90 pp. (8½ × 11), 46 il., $25.75, spiral (paper).

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $73.75.

☐ Vaughan, C. Edwin—**THE STRUGGLE OF BLIND PEOPLE FOR SELF-DETERMINATION: The Dependency-Rehabilitation Conflict; Empowerment in the Blindness Community.** '93, 256 pp. (7 × 10), 3 il., $41.00.

☐ Jones, Carroll J.—**CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 236 pp. (7 × 10), $47.75.

☐ Anderson, Frances E.—**ART FOR ALL THE CHILDREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed.** '92, 398 pp. (6¼ × 9¼), 113 il., 19 tables, $59.75.

☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $37.75.

☐ Harley, Randall K., Mila B. Truan & LaRhea D. Sanford—**COMMUNICATION SKILLS FOR VISUALLY IMPAIRED LEARNERS.** '88, 356 pp. (6¼ × 9¼), 41 il., $53.00.

☐ Fine, Aubrey H. & Nya M. Fine—**THERAPEUTIC RECREATION FOR EXCEPTIONAL CHILDREN: Let Me In, I Want to Play.** '88, 362 pp. (7 × 10), 9 il., 22 tables, $59.75.

☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), $35.75.

☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 308 pp., 13 il., 1 table,59.75.

☐ Love, Harold D. & Freddie W. Litton—**TEACHING READING TO DISABLED AND HANDICAPPED LEARNERS.** '94, 260 pp. (7 × 10), 8 il., 23 tables, $49.75.

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 284 pp. (6¼ × 9¼), 100 il., 14 tables, $42.75.

☐ Williams, Leslie A. & Lucile S. Arntzen—**A PRACTICAL APPROACH TO RSP: A Handbook for the Resource Specialist Program, 2nd Ed.** '94, 120 pp. (7 × 10), 2 il., 4 tables. $29.75.

☐ Giordano, Gerard—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $58.75.

☐ Koziol, Leonard F., Chris E. Stout & Douglas H. Ruben—**HANDBOOK OF CHILDHOOD IMPULSE DISORDERS AND ADHD: Theory and Practice.** '93, 252 pp. (7 × 10), 2 il., 18 tables, $53.75.

☐ Jones, Carroll J.—**CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '93, 272 pp. (7 × 10), $51.75.

☐ Lombana, Judy H.—**GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed.** '92, 198 pp. (7 × 10), 1 table, $45.75.

☐ Trief, Ellen—**WORKING WITH VISUALLY IMPAIRED YOUNG STUDENTS: A Curriculum Guide for Birth–3 Year Olds.** '92, 230 pp. (7 × 10), 3 il., $41.75.

☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $50.50.

☐ Fadely, Jack L. & Virginia N. Hosler—**ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS.** '92, 292 pp. (7 × 10), $49.75.

☐ Cipani, Ennio—**A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS.** '91, 268 pp. (7 × 10), 6 il., 22 tables, $52.75.

☐ Blanco, Ralph F. & David F. Bogacki—**PRESCRIPTIONS FOR CHILDREN WITH LEARNING AND ADJUSTMENT PROBLEMS: A Consultant's Desk Reference. (3rd Ed.)** '88, 264 pp. (7 × 10), $33.00.

☐ Tuttle, Dean W.—**SELF-ESTEEM AND ADJUSTING WITH BLINDNESS: The Process of Responding to Life's Demands.** '84, 336 pp., 13 il., $44.00.

Write, call (for Visa or MasterCard) 1-800-258-8980 or 1-217-789-8980 or FAX (217) 789-9130
Books sent on approval • Complete catalog sent on request • Prices subject to change without notice

2600 South First Street Springfield • Illinois • 62794-9265

Circle # 10

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages, inc.

A Model, Supportive Community For Mentally Retarded Adults

664EP School Street, Pembroke, MA 02359 (617) 293-5461

Circle # 55

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Coverage for Augmentative Communication Devices

Q In order for my daughter to participate in school, she needs an augmentative communication device. I can't afford to purchase one myself, and my insurance company says they will not cover the cost because it is not a "medical necessity." How can I get coverage for this device? Do I need a letter from a doctor saying it's medically necessary?

A There are some wonderful communication devices available for children these days. They can enable a child with a severe communication disability to communicate effectively, thus creating a foundation for education, social activities and future employment. The problem, as you already know, is that some of the devices may be expensive, and insurance companies don't always cover the costs.

The first issue in dealing with an insurance company on a problem such as this is to determine whether there is a specific policy provision that excludes reimbursement for communication equipment or "durable medical equipment." If there is no such policy provision, there's a great deal you can do to ensure that the device is paid for by your insurance company.

It's important to remember that insurance policy rules are usually very specific and extremely precise. If a product is described inaccurately, or a claim does not include all of the necessary paperwork—or "documentation"—the insurance company may not pay for it, even if the item is covered by the policy. And, in some cases, an insurance company may phrase the reason for the rejection of the claim in technical or bureaucratic terms that are difficult for a consumer to understand.

Communicating with consumers

Most insurance companies, I think, try very hard to communicate effectively with consumers. However, companies are very careful about how they phrase things these days because of potential legal implications. In addition, insurance companies generally process claims by computer, and there are only a certain number of coded sentences that can reasonably be placed on a computer.

Thus, the reason for the claim rejection printed on the EOBS ("Explanation of Benefits Statement") is likely to be in very general technical language. If an insurance company wants a letter from a medical doctor before it will pay a claim, for example, the EOBS may contain a statement such as "Documentation Incomplete" or "Not Medically Necessary."

A phrase such as "Not Medically Necessary" may sim-

860

ply mean that the insurance company cannot further process the claim until the documentation is complete. In the meantime, the claim will be coded as "Not Medically Necessary" in the computer, since the company can't verify that the equipment is medically necessary without complete documentation.

Your next step should be to find out the specific reason for the rejection of your claim. Insurance company representatives are usually quite willing to help consumers understand the claims process. If the insurance company representative who answers the phone isn't able to help, ask to speak with a supervisor. Most supervisors have been with a company for a long time, and are usually quite knowledgeable about the details of the claims process.

Prentke Romich Company, a manufacturer of communication devices, publishes *How To Obtain Funding For Augmentative Communication Devices*, an excellent booklet on filing insurance claims. The booklet, which costs $5, includes definitions of basic terms and sample letters from doctors and therapists. For a copy of this booklet, contact Prentke Romich Company, 1022 Heyl Road, Wooster, OH 44691, 800-262-1984.

Alternate sources of funding

If your insurance policy does specifically exclude communication devices or "durable medical equipment," there's really not much you can do to persuade the company to pay for the device. However, alternate sources of funding may be available.

Since communication is essential for education, for example, the local public school district may be willing to purchase a communication device for a child with a disability as long as the need for the device is noted in the child's IEP ("Individualized Educational Plan"). State agencies or charitable organizations may also be willing to purchase such a device.

I think the most important thing is not to give up until you've thoroughly explored all of the possibilities. A child's right to communicate effectively, in spite of a disability, should not to be denied for financial reasons.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To insure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking--and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 66

Special Care for Special People

Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 750-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Circle # 77

WHAT'S HAPPENING

Technology Resources

• The Electronic Industries Association (EIA), a 70-year-old trade organization

representing all facets of electronic manufacturing, offers *Extend Their Reach*, a 24-page pamphlet about assistive technology. Written as a general introduction to assistive technology, the pamphlet includes information on computers; environmental controls; telephone and communication services and funding sources to help people pay for assistive devices.

Single copies of the pamphlet are free; each additional copy is 90 cents. *Extend Their Reach*, EIA, 2001 Pennsylvania Ave., NW, Washington, DC 20006-1813, (202) 457-9752.

• *Unlocking Tomorrow* is a 56-minute documentary video on assistive technology. The video shows individuals with disabilities using a full range of assistive technology—from very simple to sophisticated adaptations—in recreation, education and employment.

The video, produced by Georgia Public Television (GPTV) with support from the Texas Planning Council for Developmental Disabilities, has closed captions and DVS (audio description for people with visual impairments).

Texas residents can obtain the video at no cost by calling (800) 262-0334 (toll-free in TX only). For all others, the video costs $30; contact GPTV Tape Sales, 1540 Stewart Ave., SW, Atlanta, GA 30310, (404) 756-4700.

• Teens with hearing impairments and their hearing friends socialize on the *PC Pals Teen Network*, a computer bulletin board on American Online (AOL), a commercial online service. PC Pals, a joint venture of the Alexander Graham Bell Association for the Deaf and Oticon, offers a special interest place for teens from across the country to discuss topics ranging from summer jobs to movies and books. There's also a chat group where up to 40 teens can "talk" to each other at the same time. Currently, the chat group meets on Sundays at 7 p.m., EST.

To use PC Pals, you will need a computer, modem, telephone line and subscription to AOL. To order an AOL starter kit and free software, call (800) 827-6364, ext. 6751. There is a monthly charge of $9.95 for five hours of connect time per month; additional usage is $3.95 per hour. AOL can also be accessed through some schools and libraries.

To find the PC Pals board, sign on to AOL and enter the keyword "deaf" to go to the deafness and hard of hearing area. Then, scroll down to and select "PC Pals Network."

For more information, contact the Alexander Graham Bell Association, 3417 Volta Pl., NW, Washington, DC 20007, (202) 337-5220 (Voice/TTY).

At Devereux . . .
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

Conversation Software for Real Communication

Talk:About™
AAC solution for your Macintosh®
New Era for Non-Speaking Persons
• conversation foundation
• fast & efficient
• share opinions and stories
DON JOHNSTON
800.999.4660 USA CANADA
708.526.2682 USA GLOBAL
Call for a demonstration disk
Discover Potential... Experience Success

Circle # 139

862

Movin' On

Movin' On is a 24-minute, close-captioned video about successful people with disabilities. Among the six individuals profiled are a hospital administrator with cerebral palsy, a chemist who has a hearing impairment, an Indiana State University undergraduate who is blind and hopes to become a lawyer and a pediatrician with spina bifida.

The video is free, but requires a $5 shipping and handling fee. Contact the Riley Child Development Center, c/o James Whitcomb Riley Hospital for Children, 702 Barnhill Dr., Indianapolis, IN 46202-5225, (317) 274-8167.

TOYS

Just in time for the holiday season, EXCEPTIONAL PARENT has compiled a list of companies which offer toys for children with disabilities and special needs. A free catalog is available from each.

Flaghouse
150 N MacQuesten Pkwy,
Mt Vernon, NY 10550
(800) 793-7900.
Adaptive toys
Circle # 29
See ad on page 29

Jesana, Ltd.
PO Box 17
Irvington, NY 10533,
(800) 443-4728.
Adapted toys, switches, activity centers
Circle # 221

Kapable Kids
PO Box 250
Bohemia, NY 11716
(800) 356-1564.
Toys, equipment, learning materials
Circle # 222

Lakeshore Learning Materials
2965 E Dominquez
Carson, CA 90749
(800) 421-5354.
Educational products, adaptive equipment, outdoor play equipment
Circle # 223

Pediatric Products
PO Box 571555
Tarzana, CA 91357
(800) 947-0947.
Medical toys and books
Circle # 253

Sportime Abilitations
One Sportime Way,
Atlanta, GA 30340
(800) 850-8602.
Recreation and exercise products
Circle # 224

S&S Worldwide
PO Box 517
Colchester, CT 06415
(800) 243-9232.
Indoor and outdoor toys and games
Circle # 225

TFH
4537 Gibsonia Rd.
Gibsonia, PA 15044
(412) 444-6400.
Toys, books
Circle # 226

Toys for Special Children
385 Warburton Ave
Hastings-on-Hudson,
NY 10706
(800) 832-8697.
Toys, switches
Circle # 194
See ad on page 72

TOYS on the MOVE

The Names They Know & Love!

* fully adapted for switch operation (some with two jacks for two different actions).
* TALK' N VIEW MAGIC MIRRORS with "Lion King", "Beauty and the Beast" or "Snow White" themes and your kids favorite pals TALKING BIG BIRD and BARNEY®, HOLIDAY TOYS & MORE ... all easily set into motion with lights, sounds and action.

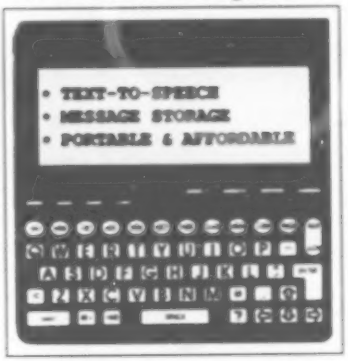
To Order or ask for our brochure phone or fax (513) 860-5475 Mon.- Fri. 8:30AM - 5:30PM (EST) or write:

SWITCH KIDS, INC.
8507 Rupp Farm Drive
West Chester, OH 45069-4526

MasterCard VISA

Circle # 282

Voice Output Keyboard
Innovations for Beginners



Franklin Electronic Publishers'
Language Master 6000
SPECIAL EDITION: $490.00

- Designed for Special Needs Users
- Keyguard $30.00 Pouch $25.00
- Picture Communication Book: $85.00

TIGER
Communication System
155 East Broad St. S-325
Rochester, NY 14604
(800) 724-7301 for video loan

Circle # 283

TheBOSS
INDEPENDENCE MOBILITY

Photo used with permission from Hedstrom Corp., Bedford, PA

SWITCH OPTIONS
PROPORTIONAL CONTROL
REMOTE CONTROL

Five Models Available

1-800-950-5185

INNOVATIVE PRODUCTS, INC.
Grand Forks, ND 58201

Circle # 42

Toys for Special Children

The people of Toys for Special Children have sought to create a new world of play for the handicapped through the development of specially adapted toys, capability switches, activity centers, augmentative communication aids, and countless other special devices for the handicapped.

Vibrating Light

Call 800-832-8697

Steve Kanor

Special Service

We offer many standard technical solutions for handicapped people. We realize that for some, special adaptions are needed. Please call us so that we can discuss fabricating custom equipment for your special requirements.

"Dr. Kanor's devices have benefits beyond words"

-The New York Times-
Oct. 20th, 1991

A unique resource for technology which can be used to increase, maintain, or improve functional capabilities of individuals with disabilities.

The Cooper Car

To get your catalog call or write to:
Toys for Special Children
385 Warburton Avenue
Hasting-on-Hudson, NY 10706
800-832-8697

Circle # 151

NEW PRODUCTS

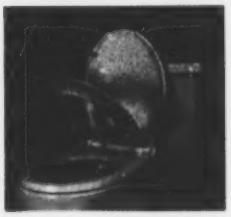
SPIFFY

This molded plastic floor sitter features tilt-in-space adjustments from 0 to 25 degrees and a strong plastic tray to provide a play surface. It is compatible with personalized seating systems up to 12 inches wide, and allows children to play and interact with their peers at floor level. This lightweight unit also provides an alternate base to a stroller, wheelchair or highchair.

Thames Valley Children's Centre, London, ONT, Canada N6C 5Y6

Circle # 155

ADULT AND BABY TOILET SEAT

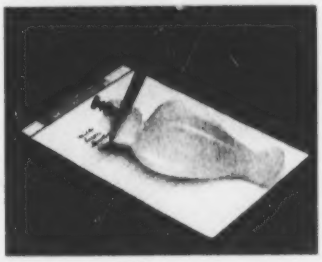


Now there's a new option for children with limited muscle control and balance. This lid attachment with a smaller opening can be used instead of toilet seat reducers and potty chairs. It also lifts and removes quickly for cleaning and so other family members can use the standard seat.

Carica, Inc., Surrey, British Columbia, Canada V4P 1M7

Circle # 156

THE WRITING BIRD

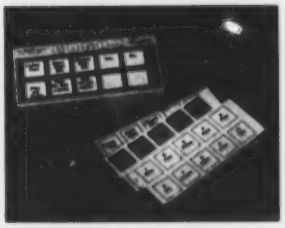


An adaptive writer to benefit individuals who need to learn to write with the non-dominant hand, or who have arthritis, neurological disorders, limited hand coordination or limited dexterity. The unit holds a retractable pen in place and allows the user to employ an arm-to-shoulder motion to write. With either the right or left hand, the user directs the unit across the page with a motion similar to that used for controlling a computer mouse.

North Coast Medical, Inc., San Jose, CA 95125-1042

Circle # 157

ACTIONVOICE



Up to 18 natural voice messages with up to two minutes total recording time can be recorded on this portable (about 13 ounces!) supplemental communicator. Adapted devices and toys can be connected to the unit with two built-in switch closure outputs. Kids can use the built-in keypad, single-switch scanning or optical pointing access when combined with accessories.

Ability Research, Inc., Minnetoka, MN 55345-0721

Circle # 158

CLICKIT!

No mouse required! Designed to work with all Macintosh programs, this utility program enhances the ability of IntelliKeys, switches or regular keyboards to provide "mouseless" access to menus, dialog boxes and scroll bars. Also allows custom overlays or switches to click on or scan "hot spots," pre-programmed, but changeable areas on the screen. For use on Macintosh SE or higher computers.

IntelliTools, Inc., Richmond, CA 94804

Circle # 159

VOICEBACHS

A self-contained system designed for powerful communication and all the wear and tear a kid can give it. Its computer brain is enclosed in a metal case in the carrying pack. The water-resistant Lynn Tablet keyboard (12″ × 10″ × 1″) features a full keypad and 16-line LCD screen display protected by polycarbonate, better known as "bullet-proof glass." The system also includes speech output through a built-in speaker and QuickTyper software to cut keystrokes in half.

Magic Laboratories, Inc., Redwood City, CA 94061

Circle # 160

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TDD, (301) 588-9284,V/TDD or (301) 587-1967, FAX.

EXCEPTIONAL PARENT *Library*

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

AUTISM

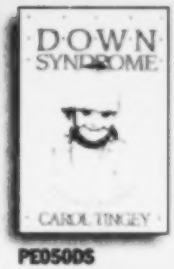
OUT OF SILENCE
A journey into language
RUSSELL MARTIN
A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.
HH083AM **$22.50**

SON RISE
The Miracle Continues
BARRY N. KAUFMAN
An awe-inspiring reminder that love made tangible can move mountains.
OI089AM **$20.00**

DOWN SYNDROME

ADVANCES IN DOWN SYNDROME
EDITED BY V. DMITRIEV & P. OELWEIN
Twenty experts contribute their recent research, experience, and thoughts on future directions for children with Down syndrome.
PE045DS **$31.00**

BABIES WITH DOWN SYNDROME
A Parents' Guide
ED. BY KAREN STRAY-GUNDERSEN
The complete guide for new parents of babies with Down Syndrome. Written by professionals and parents, this book covers everything new parents need to know.
WB010MR **$14.95**

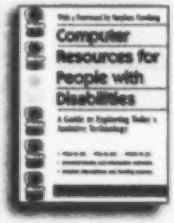


DOWN SYNDROME
A Resource Handbook
EDITED BY CAROL TINGEY
This book, written for both families and clinicians, is personal in approach and direct in style. It discusses with compassion and knowledge the genetic, medical, social, and family aspects of Down syndrome.
PE050DS **$22.00**

DISABILITY, GENERAL

ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
TONI FLOWERS
Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels.
PE035OD **$29.00**

THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
HC082OD **$12.00**



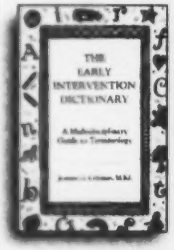
COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES: ***A Guide to Exploring Today's Assistive Technology***
THE ALLIANCE FOR TECHNOLOGY ACCESS
Provides user-friendly support, information, and up-to-date answers.
HP087OD **$14.95**

DEVELOPMENTAL DISABILITIES
Psychosocial Aspects
GEORGE S. BAROFF
In this unusually perceptive book, the author conveys the psychological and social impact of developmental disability on the individual from infancy through adulthood
PE046OD **$27.00**

DISABILITY AND THE FAMILY
A Guide to Decisions for Adulthood
H. TURNBULL, ET AL.
This practical, easy-to use guide helps answer families' questions concerning the future needs of their family members with disabilities.
PB054OD **$29.00**

DOES YOUR CHILD HAVE EPILEPSY?
2nd Edition
JAMES E. JAN, ROBERT G. ZIEGLER AND GIUSEPPE ERBA
This book provides information on the most common seizures, causes, principles of treatment, investigation and outcome, with a wide range of helpful suggestions from infancy to early adulthood.
PE036OD **$22.00**

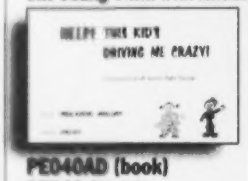
DORMAC EASY ENGLISH DICTIONARY
DOROTHEE BAKER AND CONSTANCE BETTINO
Containing 5,000 entries, invaluable to elementary and intermediate students with a reading level of approximately 1.0–4.0.
PE033M **paper** **$19.00**
PE033 **cloth** **$29.00**



THE EARLY INTERVENTION DICTIONARY
A Multi-disciplinary Guide to Terminology
JEANINE COLEMAN, M.ED.
Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.
WB030EI **$16.95**

THE *EXCEPTIONAL PARENT* 1994 RESOURCE GUIDE: ***Directories of National Organizations, Associations, Products & Services***
A valuable reference tool for parents and professionals.
EP055DR **$20.45**

HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder



L. ADKINS & J. CADY
Information about typical behavior characteristics; suggestions on how to foster the development of appropriate behavior.
PE040AD (book) **$5.00**
PE040 (tape) **$89.00**

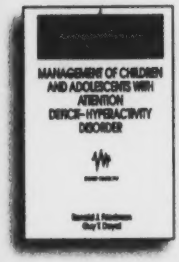
I AM, I CAN, I WILL
MISTER ROGERS
A series of audio and printed materials designed for young children with disabilities. These programs may be used to help develop a child's emotional, language, perceptual, listening and creative abilities.
15 tapes & 5 books
PE056OD **$119.00**

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
EP001EP **$14.95**

THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
WB0200D **$14.95**

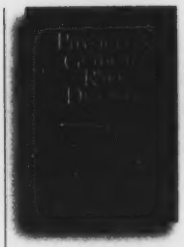
LITTLE CHILDREN, BIG NEEDS: ***Parents Discuss Raising Children with Exceptional Needs***
DON WEINHOUSE, PH.D. AND MARILYN WEINHOUSE, M.A.
What are the concerns of parents who raise disabled children? Contains candid interviews with 50 families of children with a wide range of disabilities.
RUP088OD **$12.95**

MAKING CHANGES
Family Voices on Living with Disabilities
JAN A. SPIEGLE
Shares self-reports and visions on how families and professionals make changes.
BL061OD **$19.95**



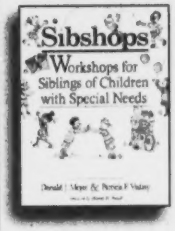
MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH ADHD
Third Edition
RONALD J. FRIEDMAN & GUY T. DOYAL
The most current medical and psychological research findings with 20 years' clinical experience. Written in a clear, nontechnical manner.
PE039AD **$24.00**

A PARENT'S GUIDE TO MIDDLE EAR INFECTIONS
DORINNE S. DAVIS, MA, CCC-A
Answering questions about ear infections in understandable terms. Anatomy, physiology and coping at home and socially.
HY090OD **$24.95**



PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP021OD **$75.50**

PLANNING FOR THE FUTURE
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP024OD **$24.95**



SIBSHOPS
Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB086OD **$32.00**

WINGS TO FLY
Bringing Theatre Arts to Students with Special Needs
SALLY DOROTHY BAILEY
A comprehensive nuts & bolts handbook for special education and drama teachers at the elementary & high school levels.
WB075OD **$17.95**

INJURY

INJURED MINDS, SHATTERED DREAMS: ***Brian's Survival from a Severe Head Injury***
JANET MILLER RIFE
Recovery and victory a family can achieve through caring.
BL067OD **$17.95**

WHEN YOUNG CHILDREN ARE INJURED: ***Families as Caregivers in Hospitals and at Home***
J. HALTIWANGER & M. LASH
A book about the family's role in caregiving when a young child is injured.
EP085ML **$7.50**

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$7.50**

WHEN YOUR CHILD IS SERIOUSLY INJURED
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$4.50**

Mail to: **Exceptional Parent,** Dept. EP9411, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents add 6% Sales Tax	
Shipping	
TOTAL	

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date ____/____

Signature _____ 867

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Circle #300 to receive a brochure of the complete library

CHILDREN'S PAGE

JOSEPH *by Teresa Schubert*

My brother's name is Joseph. He is 11 years old. Joseph goes to Parkwood Elementary School. He is in fourth grade. Joseph has a special need. He learns slower than we do. He is in a special class. He sits in a special chair when he eats.

Joseph is fun to play with! He likes to roll a ball, swing in his swing and play with balloons. But most of all, he likes to snuggle.

Seven-year-old Teresa Schubert is a second grader at Saint Thomas More School in Chapel Hill, North Carolina. She enjoys dancing and drawing. Teresa lives in Durham, North Carolina with her parents, Peter and Margaret, sister Christina, 9, and brother Joseph, 11. Joseph has trisomy 18.

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: **Children's Page,** Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005

868

LIFE

CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL® PEDIATRIC 3-WHEEL, RWD SCOOTER

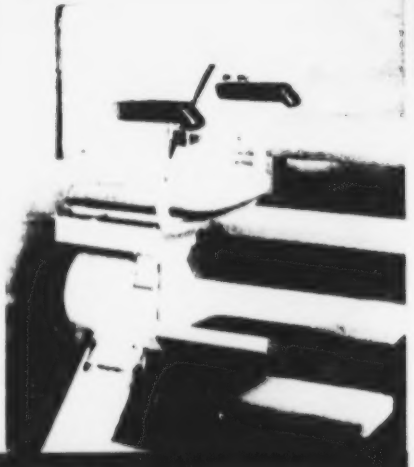
The ***REGAL PEDIATRIC*** was ergonomically designed to meet the special needs of your child. The ***REGAL PEDIATRIC*** offers these exclusive Bruno features: Custom Contoured, Adaptable Seating for superior lateral, thigh and lumbar support; 23 hardpoints in the seatback for the attachment of various support devices; slant platform for exceptional legroom; ***E-Z TILT*** ™ Tiller with all driving adjustments selectable from the seated position and overall Proportional Sizing™ for your child's specific requirements.

SCOOTER-LIFT JR® AUTOTRUNK LIFT

At Bruno we help eliminate the burdensome task of transporting your child's mobility aid. We make ***FOURTEEN DIFFERENT KINDS OF LIFTS*** for nearly any brand of scooter or wheelchair, and they can be installed in cars, vans or trucks. Bruno can help your child get around easier and make traveling a truly enjoyable experience.

CURB-SIDER® SCOOTER & WHEELCHAIR LIFT

Bruno's unique, low cost, battery-powered ***ELECTRA-RIDE*** Stair-Way Elevator can help your child get up and down stairs, easily and comfortably. No special wiring is needed and ***ELECTRA-RIDE*** will operate even if there's a power outage. Seat-Belt, Two Remote Call-Sends, Adjustable Foot Plate with Safety Sensor, Full 45-90 Degree Swivel top and bottom, including Contoured Seat, are standard. To give your child's journeys security and peace of mind.



ELECTRA-RIDE™ STAIRWAY ELEVATOR SYSTEM

BRUNO
INDEPENDENT LIVING AIDS

WISCONSIN MANUFACTURER OF THE YEAR AWARD

SPECIAL AWARD INNOVATION 1988

MANUFACTURER OF THE YEAR 1991

BRUNO INDEPENDENT LIVING AIDS, INC.
1780 EXECUTIVE DRIVE PO BOX 84
OCONOMOWOC, WISCONSIN 53066

Bruno Independent Living Aids, Inc. 1992

CALL *1-800-882-8183* **TOLL FREE OR** *1-414-567-4990* **FAX** *1-414-567-4341*

1994 BASSELL Healthcare Corporation J2170 9-94

Tumble Forms®

Happy Holidays
from
Tumble Forms.

We'll brighten your holiday season with a free subscription or renewal to *Exceptional Parent* Magazine when you order any of our Tumble Forms products. Simply mark your warranty card "Holiday Promotion" and send it to us.* This will activate your subscription.

But wait, there's more bright news! You'll also receive redeemable Tumble Forms dollars, good towards future Tumble Forms purchases.

For more information call J.A. Preston Corporation
In U.S.A. 1-800-631-7277.
In Canada call 1-800-665-9200.

* To qualify orders must be made on or before December 18, 1994 and warranty cards must be postmarked on or before April 30, 1995.

870

Circle # 7

DECEMBER 1994

EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

RELIGIOUS PARTICIPATION FOR ALL

371

For a few days, Amy will need some help... Who will volunteer?

Let Standard Publishing help you and your church better understand people with disabilities — like Amy.

JUST LIKE EVERYBODY ELSE
Jim Pierson; foreword by Joni Eareckson Tada

On a zoo outing, Derek and his granddaddy encounter a number of people with disabilities. Derek is reluctant to approach them, but he is put at ease by Granddaddy's friendly interaction with them. Later, when a disabled girl joins his class at school, he is able to welcome her "just like everybody else."

This lovingly illustrated story also includes suggestions for parents and teachers to answer kids' questions about disabilities.

24-03661 $10.99

DESIGN FOR TEACHING LEARNERS WITH DISABILITIES VIDEO SET

"This Design for Teaching video is the first thing I recommend for anyone involved in disabilities ministry," said Connie Hutchinson, a disabilities ministry director in California. "It covers everything you need to know to successfully include a child with a disability in your Sunday School class."

This powerful teacher training program shows how to include a severely disabled child in a classroom — while increasing learning opportunities for the whole class!

33-89504 $19.99

REACHING OUT TO SPECIAL PEOPLE
Jim Pierson and Robert E. Korth, Editors

This helpful book will equip your church to begin a ministry for people with disabilities. It features a Bible-teaching program with 52 lessons for those with mental retardation. It also deals with visual and hearing impairment, emotional disturbances, learning problems, and much more. One of the best ways to minister to people with disabilities is to simply be a friend. *Reaching Out to Special People* helps you do just that.

18-03139 $21.99

872

STANDARD PUBLISHING

Available from your local Christian bookstore, or call Standard Publishing toll free 1-800-543-1353

Circle # 298

J19

EXCEPTIONAL PARENT

DECEMBER 1994
VOL. 24, ISSUE 12

PARENTING YOUR CHILD WITH A DISABILITY

PAGE 22

COVER: *Seven-year-old Veronica Chloe and her mother, Sandral, attend the Ebenezer African Methodist Episcopal Church in Fort Washington, Maryland. Veronica, who has cerebral palsy, was one of the first participants in the church's Exceptional Child Ministry, established four years ago. The program offers children with disabilities the opportunity to participate in Sunday school classes, social events and the annual Christmas pageant. Beginning on page 22, you can read more about Veronica and other children with disabilities whose lives are enriched by participation in their local faith communities. Photo: Keith Mitchell*

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 12 times per year by Psy-Ed Corporation, 209 Harvard St. Ste. 303, Brookline, MA 02146-5005. All rights reserved. Copyright ©1994 by Psy-Ed Corporation. EXCEPTIONAL PARENT® is a registered trademark of the Psy-Ed Corporation. **POSTMASTER**: Please send address changes to EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Second-class postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $24.00 per year. Annual subscription rate for Canada is $30 (U.S. funds only). All other foreign countries $33 (U.S. funds only). **SUBSCRIBER SERVICE**: Direct all inquiries & address changes to: EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, N.J. 07834. Subscription Problems: Call (800) 562-1973 and ask for Customer Service. Exceptional Parent. *To place new orders, call (800) 247-8080. Libraries*: No claims honored 60 days past mailing date. Back issues requested thereafter incur a charge of $6 each and depend upon availability.

RELIGION

Religious Participation For All by Bill Gaventa 22

Catholic Life for Children with Disabilities by Marilyn Bishop 26

A Jewish Education For Every Child by Becca Hornstein 29

Toward a More Inclusive Protestant Sunday School by Brent Webb-Mitchell 31

Advocating for Access by Marilyn Bishop 33
Finding a welcoming congregation.

Faith Group Resources 38

FEATURES

For the Love of Peter by Ginny Thornburgh 41
While trying to nurture her son's gifts, a mother discovers her own.

Buying and Converting by Marc S. Malkin 45
What you need to know about van lifts and ramps.

Information Needs of Siblings by Donald J. Meyer 49
Siblings have life-long needs for accurate information.

DEPARTMENTS

Editor's Desk 2

Letters 4

Search & Respond 8

Familiar Faces 16

Fathers' Voices: A FEW MILES ON THE OL' ROCKER by Edward Sample 18

Role Models: JIMMY MULZET 35

Media: LOVING JUSTICE: THE ADA AND THE RELIGIOUS COMMUNITY 43

New Products 47

Ask the Doctor: TRANSITION TO ORAL FEEDINGS; FELBAMATE 50

Book Beat 52

Health Insurance Troubleshooter: MEDICAID AND HMOS 52

Research: ARE THEY READY TO TEACH OUR KIDS? 54
Survey shows lack of confidence in teacher readiness to deal with learning disabilities.

What's Happening 56

Directory of Advertisers 58

Informational Forum: Networking 63

Exceptional Parent Library 66

Children's Page: IF I COULD GIVE THE WORLD A GIFT by Joshua W. Humphreys 68

EDITOR'S DESK

In this issue, we celebrate religion, religious education and spirituality and illustrate the progress many faiths are making in including children and adults with disabilities and their families in community congregational life. Sadly, the important role that religious participation can play in the lives of families is rarely discussed in meetings between parents and education and health care professionals. Many professionals do not appreciate the ways a family's religious faith and participation can meet some important needs of children with disabilities and their parents.

STANLEY D. KLEIN, PH.D.

Similarly, professionals tend not to see members of the clergy as valuable allies and collaborators in efforts to advocate on behalf of children with disabilities. Such advocacy efforts are often aimed at the goal of creating more opportunities for children with disabilities and their parents to participate in day-to-day community life—but community life includes activities within local churches, synagogues and mosques.

We invited a committee of members of different faiths to help with this issue. The committee, chaired by the Rev. Bill Gaventa, included Marilyn Bishop, Becca Hornstein, Ginny Thornburgh and Dr. Brett Webb-Mitchell—each a dedicated leader in his or her faith's efforts to include people with disabilities. Committee members wrote articles and reached out to encourage individuals to share stories about the ways members of local faith communities have included and empowered children and adults with disabilities. We are very grateful to this committee and to all the other wonderful, giving people from so many faiths who contributed to this issue.

Because of all the powerful material about religion to be included in this issue, we did not have space to run an important article by Sen. Tom Harkin about health insurance reform. Despite our considerable disappointment regarding the failure of health care reform efforts in the past year, the senator's article (which we will publish in February) shows that the voices of parents have been heard by some key members of Congress; there is still hope that needed changes will occur. With the help of our readers, and advocates like Sen. Harkin, we hope that the many new members of Congress will learn to listen to and appreciate the input of parents and people with disabilities on this critical issue.

Special thanks

We appreciate the hard work of Tawanda Brocket-DeVance in setting up the photo shoot for this issue's lovely cover of Veronica Chloe and her mother, Sandral. Thanks again, Tawanda.

Looking back, looking ahead

We have been delighted by reader feedback about new departments begun in 1994—*Father's Voices, Familiar Faces, Role Models, Ask the Doctor, Health Insurance Troubleshooter* and *Research.* This month's *Fathers' Voices,* Edward Sample's "A Few Miles on the Ol' Rocker," is a powerful example of why so many readers look forward to these departments.

It has been gratifying to hear so many favorable comments from readers about how much our magazine has improved this year. Because her dedication and talent have played such a key role in the "new" *Exceptional Parent,* I am pleased to announce that Kim Schive has been promoted to associate editor.

Our editorial office has also moved to a larger space at the same address. New staff members include Marc S. Malkin, a graduate of Boston University with several years of experience as a newspaper reporter, and Leslye Sneider, a former president of the UCLA Union of Students with Disabilities.

We extend our best wishes for the holiday season and the new year to all our readers.

EDITOR IN CHIEF Stanley D. Klein, Ph.D.
Professor of Psychology, New England College of Optometry

ASSOCIATE EDITOR Kim Schive

EDITORIAL STAFF
Marc S. Malkin Leslye Sneider

EDITORIAL INTERNS
Andrea Kamens Jennifer M. Koerber
Susan S. Brody

CONSULTING EDITOR
Maxwell J. Schleifer, Ph.D.

EDITORIAL OFFICE
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
(617) 730-5800 Fax (617) 730-8742

PRESIDENT AND PUBLISHER
Joseph M. Valenzano, Jr.

VICE PRESIDENT, MARKETING Terri M. Sutera

VICE PRESIDENT, SALES Kerry J. Cannon

AD TRAFFIC MANAGER Stefanie Ferrante

CIRCULATION MANAGER Kimberly Tuzik

DIRECTOR, ORGANIZATIONAL RELATIONSHIPS R.K. Hopkins, Jr.

VICE PRESIDENT, MANUFACTURING & DISTRIBUTION Lawrence Qualiano

FINANCE MANAGER Roy Whitaker

PUBLISHING OFFICE
120 State Street
Hackensack, NJ 07601
(201) 489-0871 Fax (201) 489-1240
Advertising sales: (800) E-PARENT

SALES REPRESENTATIVES

NEW ENGLAND, DE, DC, MD, NJ, NY, PA, VA, WV, EAST CANADA
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
William Middleton
(404) 973-9190 Fax (404) 565-7013

MIDWEST (CO, IN, KS, MN, ND, So OH, SD, UT, WI)
Anthony Arnone
(708) 428-5162 Phone and Fax

MIDWEST (IL, IA, MI, MO, NB, No OH)
John Maisel
(708) 416-0780 Fax (708) 416-0793

SOUTHWEST (AR, AZ, LA, NM, OK, TX)
Jane Hayward
(714) 366-8455 Fax (714) 366-9289

WEST COAST (So CA, NV)
Richard Ayer
(714) 366-9089 Fax (714) 366-9289

WEST COAST (AK, No CA, HI, ID, MT, OR, WA, WY, BC)
William Hague
(206) 858-7575 (206) 858-7576 Fax

SCHOOLS, CAMPS, RESIDENCES, CLASSIFIED & SPECIAL SALES
Barbara Nastro
(201) 680-4874 Fax (201) 680-8355

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58. BPA International Consumer Magazine Membership Applied for August 1993.

874

Finally...Headgear designed just for little kids...

And the healthcare professionals' answer to safety.

ProtectaCap® is ideal for post-surgery and therapeutic activities. **P**rotectaCap is made with proven shock-absorbent Ensolite® foam which helps to prevent injury by absorbing the impact of a blow or fall. **P**rotectaCap's unique, expandable design provides a comfortable, custom fit for each child under six years of age. **A**nd ProtectaCap weighs only three ounces. **T**ested by safety engineers, ProtectaCap rates "excellent" in shock absorption. It replaces hard plastic by eliminating weight, heat, bacteria and discomfort. **L**ittle heads are secured quickly with a convenient Velcro® closure. And ProtectaCap is fully machine-washable. **P**rotectaCap is cute, colorful, and adds to the self-esteem of any child requiring headgear.

"We had a little girl with hydrocephalus. Because of her abnormally-shaped head, we couldn't get a good fit, even with custom-made helmets. ProtectaCap fits great and it works so well. We've been very happy with it. Other helmets are so obstrusive-looking. ProtectaCap looks so nice."
L. Sasso-Lundin, Occupational Therapist, Shriners Hospital, Portland, OR

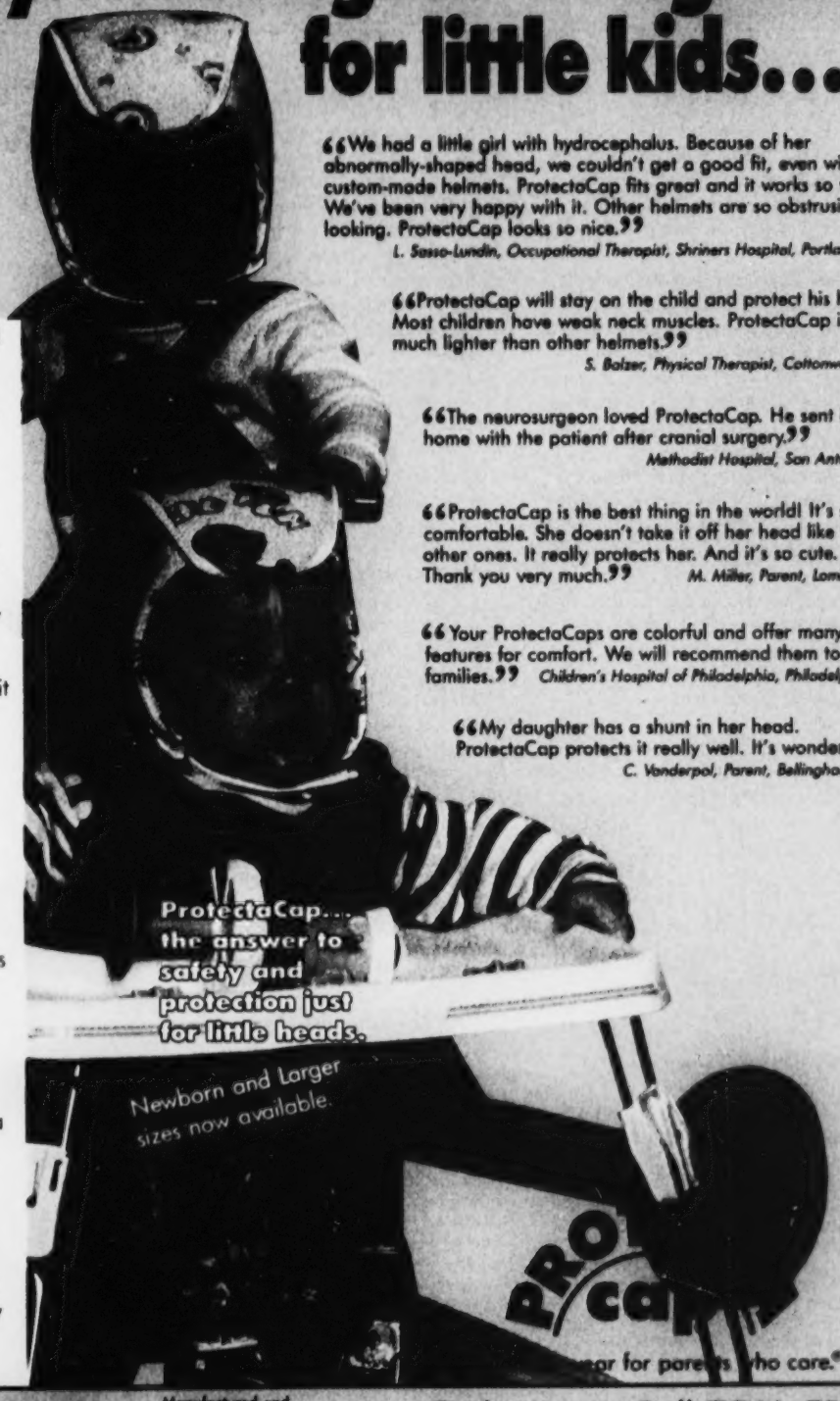
"ProtectaCap will stay on the child and protect his head. Most children have weak neck muscles. ProtectaCap is so much lighter than other helmets."
S. Balzer, Physical Therapist, Cottonwood, AZ

"The neurosurgeon loved ProtectaCap. He sent it home with the patient after cranial surgery."
Methodist Hospital, San Antonio, TX

"ProtectaCap is the best thing in the world! It's so comfortable. She doesn't take it off her head like the other ones. It really protects her. And it's so cute. Thank you very much."
M. Miller, Parent, Lombard, IL

"Your ProtectaCaps are colorful and offer many good features for comfort. We will recommend them to our families."
Children's Hospital of Philadelphia, Philadelphia, PA

"My daughter has a shunt in her head. ProtectaCap protects it really well. It's wonderful."
C. Vanderpol, Parent, Bellingham, WA



• Yellow • Pink • Light Blue • Royal Blue • Neon Pink
• Neon Green • Neon Pink/Black • Neon Green/Black
• Royal Blue/Silver • Boy Print • Girl Print

Manufactured and Sold Exclusively by:

plum enterprises, inc.
9 Clyston Circle
P.O. Box 283
Worcester, PA 19490

Order Now-Call TOLL FREE

1-800-321-PLUM

or Fax your order to 215-584-4151

DISC VISA ACCEPTED. OVERNIGHT DELIVERY AVAILABLE

$72.95, plus $7.95 S/H. **MEDICAID APPROVED.**

Circle # 239

LETTERS

A Lifeline to the USA

We are the parents of a child who is blind and has multiple disabilities. We live in Malta—that little island in the Mediterranean—and were first introduced to *Exceptional Parent* two years ago.

First of all, let us congratulate your editorial team for your comprehensive overview of the worries, joys, struggles, triumphs and day-to-day care which form part and parcel of raising our special children. Not only have I learned a lot from your magazine, it has been a source of ever-needed support to us.

Our six-year-old daughter, Hena-Marie, was born at 28 weeks gestation and has retinopathy of prematurity and mild cerebral palsy. She also has a right leg, above-knee amputation. I believe she is a unique case in Malta; as such, we have not found much professional advice regarding the hundred and one complex questions that we must tackle to enable our girl to develop her full potential.

Limitations of facilities and expertise are disadvantages of living in a country with such a small population (approximately one-third of a million people). Reading about the accurate assessment of children, and learning of all the technological advances and aids in your magazine makes us wish to just fly over to the USA to seek help for our daughter; but we certainly can't afford it. We worry that we are not providing her with the services and environment needed to enhance her development, though we know she is getting the best possible care under the circumstances. Such feelings are quite disheartening. Nevertheless, we carry on in our search for answers both locally and abroad. This is why we consider *Exceptional Parent* our lifeline to the USA.

S.B., Malta

Inclusion and Ideology

It was with dismay, disappointment and disillusionment that I read Albert Shanker's *Inclusion and Ideology* (September 1994). I am a parent who looks forward each month to your magazine. Usually, it gives me information to help me with my child's school, health and social life. Reading this magazine has always given me a sense of hope because it lets me know I am not alone. I respect the viewpoints of other people and do not expect everyone to agree with me all the time. I respect the opinions of professionals who are trained in certain areas and who are experienced in working with children who have disabilities. I especially respect the opinions of parents because I believe they know what is best for their child and family. If any of these people had written an article on inclusion, I would have read it with interest and tried to learn from it. Instead, you chose to reprint an old

Tell us about...

...your family's most memorable vacation.

(Did you pick up any tips you could pass along to other families planning trips with a child who has a disability?)

Write to: *Vacation, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

EXCEPTIONAL PARENT

- ***To reach out to parents of children with disabilities and special health care needs.***
- ***To empower mothers and fathers by providing practical information and emotional support.***

EDITORIAL ADVISORY BOARD

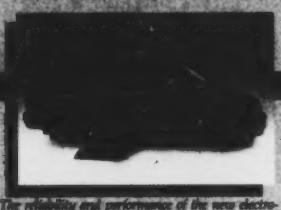
LISA BLUMBERG, J.D., Corporate Attorney, Aetna, Hartford, CT
T. BERRY BRAZELTON, M.D., Clinical Professor Emeritus of Pediatrics, Harvard Medical School, Boston, MA
FRANCES P. CONNOR, Ed.D., Professor Emerita, Special Education, Columbia University Teachers College, New York, NY
ALLEN C. CROCKER, M.D., Director, Developmental Evaluation Center, Children's Hospital, Boston, MA
ELI FACTOR, D.M.D., Parent, President, Wheelchair Motorcycle Association, Brockton, MA
MURRAY FEINGOLD, M.D., Physician-in-Chief, National Birth Defects Center, Waltham, MA
SANDRA B. FLEISHMAN, Parent, Project Director, A WORLD OF DIFFERENCE Institute, Anti-Defamation League, Boston, MA
BRUCE M. GANS, M.D., President, Rehabilitation Institute of Michigan, Detroit, MI
SOL GORDON, Ph.D., Professor Emeritus, Child and Family Studies, Syracuse University, Syracuse, NY
STANLEY I. GREENSPAN, M.D., Clinical Professor of Psychiatry and Behavioral Pediatrics, George Washington University Medical School, Washington, DC
HERBERT J. GROSSMAN, M.D., Professor of Pediatrics, Neurology, and Psychiatry, Univ. of Michigan Medical Center, Ann Arbor, MI
DAVID HIRSCH, M.D., Phoenix Pediatrics, Phoenix, AZ
GOODWIN D. KATZEN, Former Executive Director, Rockland County Center for the Physically Handicapped, Pomona, NY
SUSAN M. KLEIN, Ph.D., Professor of Special Education, School of Education, Indiana University, Bloomington, IN
DINA LOEBL, Ed.D., OTR, Associate Professor, Department of Occupational Therapy, School of Education, New York University, New York, NY
EDWIN W. MARTIN, Ph.D., President Emeritus, National Center for Disability Services, Albertson, NY
JAMES MAY, M.A., M.Ed., Project Director, National Fathers' Network, Bellevue, WA
JEAN B. McGREW, Ph.D., Superintendent, Glenbrook School District #225, Glenview, IL
EDWARD NEWMAN, Ph.D., Professor, Temple University School of Social Administration, Philadelphia, PA
BETTY PENDLER, M.S., Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY
STEVEN P. PERLMAN, D.D.S., M.Sc.D., Assistant Clinical Professor, Boston University School of Dentistry, Boston, MA
HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA
SIEGFRIED M. PUESCHEL, M.D., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
PEGGY MANN RINEHART, R.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
IRVING KENNETH ZOLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

876

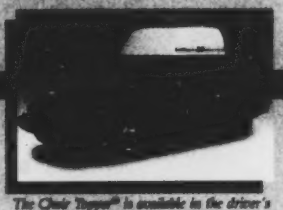
BRAUN

The new Lift-A-Way D/C® is the latest in the Braun line of ARS (Automatic Roll Stop) equipped lifts. The inherent design of the ARS engages the roll stop before there is any vertical platform movement.

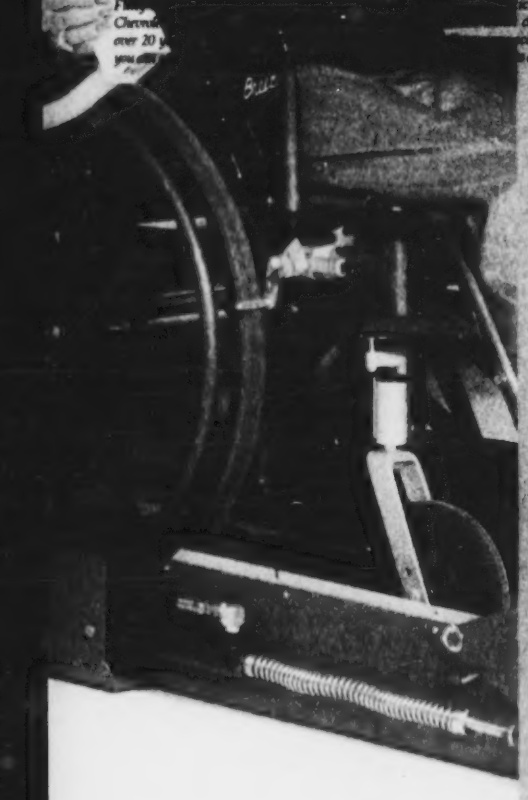
...ic rear post Swing-A-Way® lift ... door push account in the industry. ...ccess for cargo and ambulatory ...s a clearer side view for the driver.



The reliability and performance of the new electro-mechanical touching system sets the Braun Entervan™ apart from other low floor minivans.



The Chair Topper® is available in the driver's side configuration or the optional passenger side design. Due to its horizontal operation, it may be used inside standard garages.



International Leader in Personal Mobility Products

The Braun Corporation has established their products as the benchmark for International Personal Mobility. The new Lift-A-Way D/C® continues Braun's reputation for dependability and excellence.

Braun's nonskid yellow ARS (Automatic Roll Stop) engages before any vertical platform movement. Boasting the lowest loading ramp angle in the industry, the ARS makes it easy to load both power and manual wheelchairs onto the platform.

Dual locking handrails contribute to a secure environment while on the lift platform. Other safety features include yellow demarcation of the wheelchair loading boundaries and an override circuit which prevents the Lift-A-Way D/C® from folding when there is weight on the platform.

No matter what your needs, Braun has a mobility system designed for you. The original Lift-A-Way® platform lift is a reliable performer proven with over two decades of use. For greater ambulatory and cargo access, we offer the Swing-A-Way®. The lowered floor Entervan™ is the perfect choice for the individual or small family. And, for the person who transfers, the Braun Chair Topper® conveniently stores a conventional folding wheelchair out of your way.

The Braun Corporation. Mobility at its best.

THE BRAUN CORPORATION.

"Providing Access to the World"

1-800-THE LIFT

The Braun Corporation is the international leader in mobility products. With four divisions and a worldwide distributor network, we are positioned to provide the equipment and services you need. Our commitment to your satisfaction is also supported by our Three-Year Worry-Free Limited Warranty. Simply call 1-800-THE-LIFT for the Braun dealer nearest you.

© 1995 Braun Corporation, Inc. B-80-150

Circle # 118

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242
800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES
A Division of Protective Life Insurance Company

Circle # 26

Our prices make everyone happy!

Send for a free catalog of adaptive equipment.

equipment shop
P.O. Box 33 • Bedford, MA 01730
(617) 275-7681 • Fax (617) 275-4094

Circle # 25

article written by a union official who does not work with children who have special needs and who is absolutely opposed to any type of inclusion program.

My child has severe mental retardation. He has been included for two years and is doing things that we never thought would be possible. The biggest gain has been for the other children in his classes. They have accepted Ben as they would any other child. He is invited to their parties and their homes, they come to his home and they all get along. These children will grow up to be better adults because of their experiences with Ben. They will be more accepting of everyone, regardless of their differences. Isn't that what inclusion is all about?

Your magazine is very important to parents; please use more consideration in the future. Yours is the only magazine that gives us the opportunity to hear each others' voices—that is what is most important. Articles about education programs should be written by qualified professionals who care about our children or parents who can speak from experience. I believe this is the least we should expect from your excellent magazine.

—J.C., Virginia

EDITOR'S NOTE: Our goal in the September issue was to provide a range of perspectives from leaders in the field of education. —S.D.K.

Two Children with Spina Bifida?

After reading the response to D.H. & D.H. (August 1994) about the family who had a second child with spina bifida, I felt compelled to write.

In the United States, one in 1,000 babies is born with a neural tube defect—spina bifida is the most common. If a mother already has one child with a neural tube defect, her risk of having a second child with a neural tube defect increases to one in 30.

The most important news about neural tube defects is that they can usually be prevented. Recent studies have shown that mothers who take the B vitamin—folic acid—immediately before pregnancy and during the first two months of pregnancy, dramatically reduce the risk of these defects in their babies.

If you are a woman who has already had a baby with a neural tube defect, and who hopes to have another child, you should take 0.4 milligram of folic acid daily. This amount of folic acid is available in many brands of non-prescription multi-vitamins or can be taken separately. During the time you are actively trying to become pregnant, change the supplement to four milligrams of folic acid each day. This must be obtained as a prescription from your doctor. Do *not* try to increase the folic acid dose by taking additional multi-vitamin tablets; this may cause you to receive a dangerous overdose of other vitamins.

If you become pregnant, continue the four milligrams of folic acid until your first pregnancy visit, at which time your doctor can advise you about pregnancy vitamins.

—D.M., South Carolina

EDITOR'S NOTE: The advice in D.M.'s letter has been reviewed and confirmed by medical experts.

878

A U N

New
Out

The Perfect Companion

The Braun Companion Seat®

If you have difficulty entering and exiting your vehicle, the new Companion Seat® is your key to greater mobility. Its automatic operation and rugged construction enable semi-ambulatory persons to reliably and conveniently board Dodge Caravan or Plymouth Voyager minivans.

The seat extends 20" and tilts forward a full 6" to make boarding safe and easy. Once on the seat, you are smoothly raised into the vehicle by pressing the conveniently mounted switch. All you have left to do is manually rotate into the forward facing position. To exit, the procedure is simply reversed.

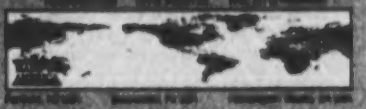
The Companion Seat® utilizes your van's original seat, but replaces the existing seat base with a unique power base. When not needed, it functions exactly as the passenger seat. This feature makes it perfect for active families with only one member who needs assistance. And, as always, Braun thoroughly tested the Companion Seat® to meet all applicable federal motor vehicle safety standards.

If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braun distributor about other sources of assistance.

For more information on the Companion Seat® or other Braun mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

Now more than ever, mobility is one of the most important things in your life. Let Braun and the Companion Seat® be the answer to your needs.

Patents Pending



The Braun Corporation is the international leader in mobility products. With four divisions and a worldwide distribution network, we are committed to quality, personal and creative problem solving. Our commitment to your satisfaction is also supported by our Three-Year Warranty. For further information, simply call 1-800-THE-LIFT for the Braun dealer nearest you.

© 1988 Braun Corporation, Inc.

SEARCH

Seventh Chromosome Deletion

My five-year-old daughter, Vanessa, has two larger diagnoses and some smaller ones as well. When she was born, doctors told us she had intrauterine growth retardation (IUGR). Almost three years later, we found out that she has a seventh chromosome deletion (band 7q 36.2). She has also been diagnosed with attention deficit hyperactivity disorder (ADHD).

Vanessa is not adjusting well to the medications for her ADHD. On some of the medications she has even become very dangerous to herself and to others around her. When her medication is working, she is a sweet little girl; when her medication isn't working, she hurts herself, screams, hits others, bites and throws things.

Right now, Vanessa weighs about 23 pounds and is 35 inches tall. She does not see or hear very well. She has very poor muscle tone. She has a high palate and poor teeth. She does not sit still for more than a minute or two, but she is very cute.

I don't have very much information on IUGR and doctors tell me there is no other child in the world with a similar chromosomal deletion. I know Vanessa will be very tiny and will have developmental delays. I know that her vision and hearing will deteriorate and that she will have small changes in the formation of her hands, feet, ears and toes. But there are so many questions I have unanswered. Is there anyone out there who has a child like my daughter? Can anyone recommend a source of information?

T.T., Minnesota

SEARCHING FOR A PEN PAL?

See page 52!

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5006
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1994 Resource Guide* (January 1994).

Chronic Guillain-Barre Syndrome

I am the mother of 12-year-old identical twin daughters. One of the girls, Melissa, has chronic inflammatory demyelinating polyneuropathy, also called CIDP or chronic Guillain-Barre syndrome. Her sister is healthy.

Melissa is doing quite well now, but has had four exacerbations of CIDP during the last five years. The weakness and paralysis come on rather suddenly, usually within 24 hours. Each time, she has been unable to walk for five to 10 weeks. Gradually, the paralysis leaves. The muscle weakness is often accompanied by a burning, tingling, pins-and-needles type of pain, particularly in her feet. She also experiences migraine headaches, extreme fatigue and a distorted sense of touch and temperature. Between relapses, her health and strength are normal. Her residual problems include difficulty with prolonged walking and standing, low stamina and some foot and leg pain. Melissa has no deep tendon reflexes; she also has some atrophy in her feet.

I am interested in hearing from other families who have children with CIDP. I want to help develop a national registry of these children so some significant research could be conducted on this rare disorder.

P.S., Nebraska

EDITOR'S NOTE: Guillain-Barre Syndrome Foundation International (P.O. Box 262, Wynnewood, PA 19096, 215/667-0131) can provide information on CIDP and help you get in touch with other organizations.

Congenital Fiber-Type Disproportion

Our three-year-old daughter, Alisha, may have congenital fiber-type disproportion. Doctors tell us she has not been given a formal diagnosis because this condition varies with each child.

Because Alisha has overall muscle weakness, she has had numerous bouts with pneumonia. She also has scoliosis. She is not able to walk or crawl, but can sit unaided. In addition to occupational and physical therapy every week, we work with her at home. At times, Alisha seems to regress and then, after a period of time, she comes out of the regression. We have no idea what causes these periods.

We are grateful that she is very bright. There is nothing wrong with her mental capabilities or speech. We would like to hear from other parents who have children with this diagnosis to hear how they are doing.

J.H. & J.H., Illinois

EDITOR'S NOTE: According to the Muscular Dystrophy Association (MDA), congenital fiber-type disproportion can be a symptom of many conditions. Your local MDA chapter (2500 Galen Dr., Champagne, Ill 61821, 217/351-1853) can refer you to medical and other resources.

Deafness and Motor Impairments

Our beautiful five-year-old daughter, Eleanore, was born with profoundly hypotonic muscle tone and right-side hemiplegia (cerebral palsy), but has always been exceptionally visually alert and socially aware. She has made steady progress in motor skills but has not developed language; this was always attributed to the neurological impairment. In July, we learned that she is profoundly deaf. We have been working with her educational program to address her deafness and lack of language, and our family is learning sign language. We know parents of other deaf children, but they all are able-bodied and were diagnosed much earlier than Eleanore. Eleanore uses a wheelchair; she has limited use of her right hand and decreased coordination with

continued on page 11

860

YOU **NOW** CAN GET A COPY OF THE MAGAZINE THAT HELPS YOU PARENT YOUR CHILD WITH A DISABILITY

12 TIMES A YEAR!!!

THAT'S RIGHT, **EXCEPTIONAL PARENT** MAGAZINE WILL BRING YOU THE INFORMATION YOU WANT AND NEED MONTHLY!

LOOK FOR OUR NEW DEPARTMENTS:

- FATHERS' VOICES
- ROLE MODELS
- ASK THE DOCTOR
- RESEARCH

EXCEPTIONAL PARENT 12 TIMES A YEAR!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

_____

Address _____

_____

City_____State_____Zip _____

Please allow 4–6 weeks for delivery 34N

EXCEPTIONAL PARENT 12 TIMES A YEAR!!!

Yes, I want to subscribe to Exceptional Parent magazine!

- ❑ One Year (12 issues) for $24*.
- ❑ 3 Years (36 issues) for $54*.

BEST BUY!

** US funds only. Canada $30 per year. Other foreign countries $33 per year.*

- ❑ Bill me
- ❑ Check enclosed *(use separate envelope)*

To order by Credit Card call: 1-800-247-8080

Please send my subscription to:

Name _____

_____

Address _____

_____

City_____State_____Zip _____

881

Please allow 4–6 weeks for delivery 34N1

No Postage Necessary If Mailed In The United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

No Postage Necessary If Mailed In The United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 241 DENVILLE NJ

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 3000 DEPT EP
DENVILLE NJ 07834-9919

YOU **NOW** CAN GET
A COPY OF THE
MAGAZINE THAT HELPS
YOU PARENT YOUR
CHILD WITH A
DISABILITY
12 TIMES A YEAR!!!

THAT'S RIGHT,
EXCEPTIONAL PARENT
MAGAZINE WILL BRING
YOU THE INFORMATION
YOU WANT AND NEED
MONTHLY!

LOOK FOR OUR NEW DEPARTMENTS:

- FATHERS' VOICES
- ROLE MODELS
- ASK THE DOCTOR
- RESEARCH

See reverse side for subscription details

her left hand. Hearing aids do not seem to help. She has the language skills of an infant, but appears to have good potential to learn.

We would love to hear *positive* stories (only positive!) about children with motor impairments and deafness, especially when the deafness was diagnosed late. We want to know about sign language acquisition by and resources for deaf children with multiple challenges.

T.K., Montana

Loud Noises in Public

Our six-year-old daughter, Kaitlyn, has severe intellectual disabilities. She has a combination of very different characteristics that do not seem to fit any one syndrome. We do not feel she is autistic. Rett syndrome has also been ruled out.

Kaitlyn does not talk. However, at times, she makes loud noises and high-pitched screams. She has been toe-walking since age three. She does not like to make eye-contact directly, but prefers to look from the side. She is happiest wandering around, picking up objects and dropping them. She has no interest in playing with others or with toys. She does not like anything that requires a lot of effort. Kaitlyn has a constant need to touch objects and put them in her mouth—this started when she was five years old. When frustrated, she will bite the closest object. She can feed herself with a spoon and drink from a cup, but is very messy. She shows no interest in potty training.

Our main concern is the loud noises she makes, especially in public and around large groups. We do not know how to get them down to a reasonable pitch, and are especially concerned about how this will be handled when she goes to kindergarten next fall. We want to hear from anyone who has dealt with a child who has similar characteristics, especially the loud noises.

G.W. & J.W., Indiana

Therapeutic Recreation

Our community is working to establish a recreational program that includes children with disabilities. We are looking for information on established therapeutic recreational programs and how these programs have been funded.

E.W., Georgia

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438
Haverich
ORTHOPAEDIC CYCLES
Europe's leading line of specialized bicycles, tricycles and tandems now available in North America.
Steel frame. Duel caliper, drum and coaster brakes available.
Parking brakes standard.
Latest styling and wide choice of colour combinations.
More than 30 specially designed accessories to meet every need.

Circle # 36

RESPOND

Augmentative Communication Aids

D.F. (October 1994) is the parent of a boy with a physical disability affecting only his gross motor skills; his fine motor skills are good. D.F. was looking for information on augmentative and alternative communication (ACC) devices because her son has just started school.

As suggested in the Editor's Note following your original *Search* letter, the article in the June 1994 issue of *Exceptional Parent* magazine is a good place to start your search because it gives an overview of the factors you should consider when selecting an ACC device. Our experience may also be helpful to you.

My seven-year-old son has multiple disabilities and is nonverbal. Due to significant physical disabilities, sign language was never a viable option. Ryan's first exposure to an ACC device came in preschool. However, he was unable to activate the device used in his classroom because he could not press the pictures hard enough.

After my repeated requests, he got a Prentke Romich IntroTalker, a device commonly used with preschoolers. Although Ryan could activate the device, he did not seem to relate to the recorded voice, that of an adult female. And because the number of items on the device was limited to eight, he quickly lost interest in using it.

Finally, a friend referred me to a voice output device called the Dynavox (manufactured by Sentient Systems, 2100 Wharton St., Ste. 630, Pittsburgh, PA, 412/682-0144). As soon as I saw this device, I thought it might be something my son would like. I was right. The key seemed to be that Ryan was motivated by the voice output, which sounds very much like a boy of his age. He finally had a voice. Now, I worry that my nonverbal son talks too much!

Perhaps you can visit an ACC center that has a variety of devices for you and your child to look at and try out. Professionals are helpful in identifying appropriate devices, but remember, you know your child best and should not hesitate to use that knowledge in selecting a device. It's also important to find a device that motivates your child; if the child does not like the device, its "appropriateness" really doesn't matter.

We chose the Dynavox for a number of reasons—we found it easy to program (all the picture symbols are already in the computer), it was easy for my son to use and it will grow as his language grows. But most of all, we chose this device because he loved it!

R.C., Maryland

☐ My five-year-old son, Frankie, has cerebral palsy and is non-verbal. Like your son, Frankie has great fine motor skills even though his gross motor skills are not so good.

We recently purchased the AlphaTalker from the Prentke Romich Company (1022 Heyl Road, Wooster, OH 44691, 800/262-1984). This device is wonderful! It has enabled him to express his wants and needs, and the whole world now views him differently.

We tried several different devices, but this was definitely the easiest to program. The Prentke Romich staff is very helpful; they even helped us get funding to buy the device. Their payment and rental policies are great; you can trade in used devices for credit as your child's needs change.

M.D., Massachusetts

Down Syndrome and Nonverbal

K.E.'s (October 1994) seven-year-old daughter, Jennifer, has Down syndrome. Jennifer was able to say about 75 understandable words by the time she was two and a half, but stopped talking a year later after frequent ear infections. Jennifer, who has received ongoing, intensive speech therapy, vocalizes but says nothing understandable. She has learned some sign language, but her signs are poorly-formed and inaccurate. She has begun to use an augmentative communication device, but uses it mostly to respond rather than to initiate conversations or make requests. K.E. wanted advice and support.

I also have a child with Down syndrome, but unlike your daughter, my six-year-old son talks all the time. I thought you might find it helpful if I tell you some of the things I have done with him.

My first recommendation is to avoid the rush to words! If we pressure a child to talk before she is ready, it will actually discourage her. Your daughter must first enjoy being with people, and prefer this to being alone. Play and interact with her as much as you can. Stop what you are doing frequently, just to spend some time with her. It doesn't have to be a lot of time, just do it often when you are both at home. It's important that children with language delays play and interact with others as often as possible, so they don't become "socially isolated."

Second, I suggest *you* don't talk too much! We parents are often told to "bathe" our child in language. But sometimes we end up "drowning" our children with words they can't yet say! Instead, keep your language short and simple. In the beginning, use just one or two words that she can try to say during an interaction. Then wait and give her a chance to do or say something. And I mean *something*—just whatever she can do or say, even if it is unintelligible at first. This will teach her turn-taking.

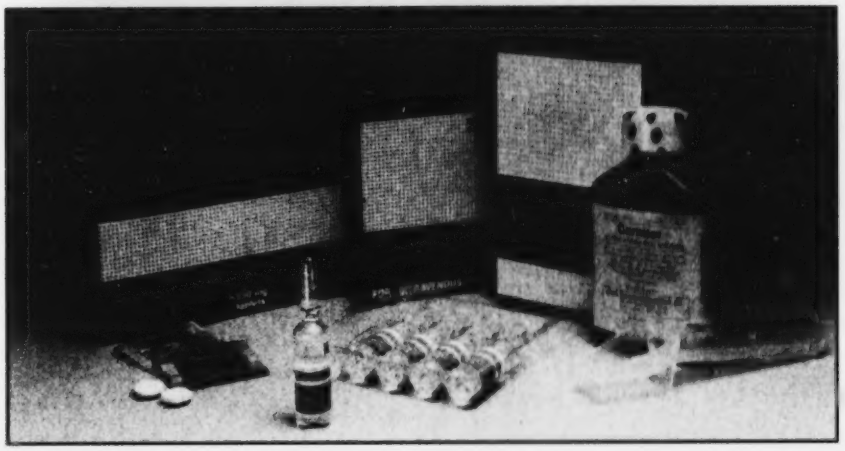
This waiting sounds very easy, but it's not. Most adults have a very difficult time waiting for a response from a child who has a language delay, but it is important that you do this; otherwise your daughter may become just a passive observer of everyday life, like so many children with developmental delays. Help her become a real participant by waiting for a response each time you say or do something.

Third, follow her lead in whatever she is doing, as often as you can. In other words, don't become the "director" of each interaction! If she is playing with her toys, quietly join in. Imitate her actions and sounds, then add simple ones of your own. Play and talk in ways she is able to imitate, not in ways that are too difficult for her to try.

Fourth, keep her interacting. By that, I mean don't let her leave an interaction right away, but try to keep her with you for a few more turns each day. It really isn't that hard if you can make yourself more fun and interesting than whatever is distracting her. (And turn off the television if she spends a lot of time watching. TV won't help her learn to communicate!)

continued on page 15

THE ONLY PRESCRIPTION FORMULATION OF LEVOCARNITINE IS NOW AVAILABLE FOR REIMBURSEMENT



- CARNITOR® (levocarnitine) is now available for reimbursement by Medicaid in all 50 states and Medicare in many states.
- CARNITOR® is the only prescription formulation of levocarnitine available and "...should not be confused with dietary and health supplement L-carnitine products.... Such supplements have not undergone review by FDA for safety and effectiveness."[1]
- "Unless these dietary supplements...have been approved...recommendations/ requirements by State Medicaid agencies would be inappropriate for the treatment of systemic carnitine deficiency."[2]
- **"The data from this and previous studies indicate a lack of quality control in the manufacturing process of tablets and capsules in products sold as food supplements, resulting in gross inconsistencies in the properties of the tablets to disintegrate under physiological conditions within a reasonable time. Furthermore, there is evidence that many of the products contain significantly less than the stated amount of the active substance, suggesting also a lack of quality control in the formulation of the product."**[3]
- **"Only the prescription form of levocarnitine is indicated for the treatment of carnitine deficiency. Over-the-counter and health food store products should never be substituted."**[4]

CARNITOR®
(LEVOCARNITINE)

**The Only Prescription Formulation!
Available in Tablets, Oral Solution,
and Ampoules for Intravenous Use...
And *Now Available for Reimbursement!***

Please see full prescribing information on adjacent page. 885 Circle # 269

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

CARNITOR®
(LEVOCARNITINE)

The Only Prescription Formulation! Available in Tablets, Oral Solution, and Ampoules for Intravenous Use... And *Now Available for Reimbursement!*

References: 1. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written communication from the Food and Drug Administration. 2. Data on file. Sigma-Tau Pharmaceuticals, Inc. Written Communication from the Department of Health and Human Services. 3. American Medical Association. Therapy for inborn errors of metabolism. *Drug Evaluations*. Spring 1992: 8:I-8:5. 4. Millington DS, Dubay G. Dietary supplement L-carnitine: analysis of different brands to determine bioavailability and content. *Clin Research & Reg Affairs*. 1993;10(2):71-80.

CARNITOR® (LEVOCARNITINE) Tablets and Oral Solution
For oral use only. Not for parenteral use.

CARNITOR® (Levocarnitine) Tablets (330 mg)
CARNITOR® (Levocarnitine) Oral Solution
(1 g per 10 mL multidose)

CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency.
Tablets and Oral Solution are also indicated for the acute and chronic treatment of patients with an inborn error of metabolism which results in a secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS

General CARNITOR® Oral Solution is for oral/internal use only. **Not for parenteral use.** Gastrointestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3-4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests have been performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* that do not indicate that CARNITOR® is mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or whether to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion

Reference: Rebouce CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D, L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D, L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® Tablets: Recommended adult dosage is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution.
Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED CARNITOR® Tablets are supplied as 330 mg, individually foil-wrapped tablets in boxes of 90. Store at room temperature (25°C/77°F). CARNITOR® Oral Solution is supplied in 118 ml (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection
For Intravenous Use Only

CARNITOR® (Levocarnitine) Injection 1 g per 5 mL
CARNITOR® (Levocarnitine)
Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS
Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests performed in *Salmonella typhimurium*. *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion
Reference: Rebouche CJ, et al: Carnitine metabolism and deficiency syndromes. Mayo Clin Proc 58:533-540, 1983.

Pediatric use See **Dosage and Administration.**

ADVERSE REACTIONS Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology.

OVERDOSAGE There have been no reports of toxicity from levocarnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea.

DOSAGE AND ADMINISTRATION
CARNITOR® injection is administered intravenously.
The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter), and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

HOW SUPPLIED CARNITOR® (Levocarnitine) Injection, 1 gram per 5 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton.

Store ampoules at room temperature (25°C/77°F) in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

sigma-tau Pharmaceuticals, Inc.
Gaithersburg, MD
A leader in metabolic research

STDLN7286/94

BEST COPY AVAILABLE

886

© 1994, SIGMA-TAU Pharmaceuticals, Inc.

Continued from page 12

And one last, very important thing—don't ask too many questions. Questions can put children with language delays "on the spot" because they have a difficult time answering. Don't use questions as a way to start an interaction or conversation. Instead, try making a comment on something you see or something your child is doing, then give her a chance to respond.

I'm sure if you try some of these ideas, you will see more communication from your child!

B.M., Ohio

Identical Twins Who Are Different

D.C. (October 1994) is the mother of 10-month-old identical twin boys. Due to a complication of pregnancy called twin-to-twin transfusion, blood intended for one twin (the donor) was diverted to the other (the recipient). They were born seven weeks prematurely. One twin (the donor) has been diagnosed with spastic quadriplegic cerebral palsy and a vision impairment. The other twin is developing normally. D.C. wanted suggestions for coping with the problems that arise from having two children with the same chronological age but different developmental ages.

My sons, Levi and Luke, are four-year-old fraternal twins. They were born seven weeks prematurely. Luke, the second-born, was breech and had more difficulties than his twin.

When the boys were 11 months old, both were diagnosed with cerebral palsy—Levi, "mild" and Luke, "severe." Now, however, Levi shows no signs of cerebral palsy, while Luke is moderately affected.

I believe Levi has been a continual motivator for Luke to do as much as he can. We have made a special effort to include Luke in *everything*, no matter how difficult. I've tried to keep the boys together as much as possible.

It was very difficult for us when Levi was achieving various developmental milestones and Luke was not. At this point, Luke crawls and walks with a walker. Both boys have started asking "why" questions.

I belonged to a Mother of Twins Club and found it to be *useless*. I was the only mom with differently-developing twins. A group called Mothers United for Moral Support (MUMS, c/o Julie Gordon, 150 Custer Ct., Green Bay, WI 54301) may be able to help you find other mothers of differently-developing identical twins. I have found this group to be a great resource.

L.A., Minnesota

EDITOR'S NOTE: MUMS makes an effort to match members who are dealing with similar situations and disabilities. The organization's most recent parent-to-parent list of disorders includes 11 families of twins in which one twin has cerebral palsy.

I had been meaning to write my own *Search* letter. Then, I saw yours, stopped everything and got out paper and pen.

We are also very proud parents of identical twin boys. Like you, I had complications with my pregnancy. Five months into the pregnancy, an ultrasound revealed twins, but doctors were concerned that "twin B" was much smaller. After a month, his growth had fallen further behind. At the very end of my sixth month, I went into the hospital for a "routine" ultrasound and was admitted 15 minutes later for toxemia.

The next day—10 weeks before my due date—our boys were delivered by emergency cesarean section.

The boys are now 27 months old. Like your "donor," "twin A" has cerebral palsy and a cortical visual impairment. His brother, "twin B," was in the hospital for 14 months and is now at home. He is fed through a g-tube and is on a ventilator with 22-hour-a-day nursing care. Mentally, they are both pretty sharp. "Twin A's" physical condition keeps him from doing what his mind is capable of. "Twin B" has about a 30-word vocabulary in sign language and is starting to crawl, however his vent and his many tubes limit him.

I am 17 months ahead of you. I wish I could tell you differently, but it really doesn't get much better. I joined the Mothers of Twins club even before the boys were born. Their support has been great, however, they all have "normal" lives and "normal" children so there is a lot we *don't* have in common.

Believe me, I know how you feel. It's very lonely not fitting in anywhere. I just get up every day and do the best I can to make my kids the best they can be—just like any other mom.

J.F., Washington

Now he has a place for everything like everyone else.

When he's at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

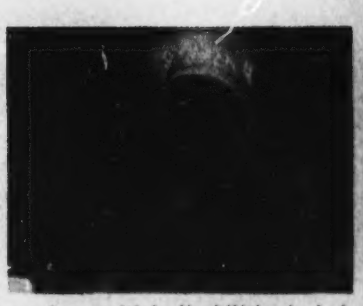
1-800-4-MYDESC

RHAMDEC

Rhamdec, Inc. • 476 Ellis Street, Mountain View, CA 94043-2240
MYDESC is a trademark of Rhamdec, Inc.

Circle # 103

FAMILIAR FACES



*The parents of two-year-old **Jordan Arkontaky** call her their "bundle of joy." Jordan, who lives in Hawthorne, New York, where winter outings require serious bundling up, has multiple disabilities including low muscle tone and cortical blindness. She enjoys listening to music and being tickled by big sister Justine.*

***Megan Jane Carroll**, 11, enjoys nothing more than "borrowing" mom Judy's makeup, jewelry and clothes. On one such occasion, Megan's "best buddy" and former teacher, Barbie Nelson, used Judy's camera to snap a picture. Mom was pretty surprised when she picked up the photos from that roll of film! The hat, incidentally, is Megan's own creation—made of painted newspaper, sunflowers and lace. Megan has Rett syndrome and lives in Dothan, Alabama.*

*Thirteen-year-old **Gina Gargiulo** of Largo, Florida celebrates fifth-grade graduation and her selection as Student of the Year with her pals at Walsingham Elementary School. Gina, who has arthogryposis multiplex congenita, is surrounded by **Jonathan Pickett**, **Camille Gentry** (teacher's aide) and **Harold Keaton**. Now, it's on to middle school for this group of friends!*

***Brothers Billy and Christopher Stoddard**, ages two and three, enjoyed a visit to the San Diego Zoo with their father **Jack**. The boys didn't get to pet any lions or tigers as they had hoped, but they still had fun wearing their parents out. The Stoddards, who live in Las Vegas, Nevada, were in San Diego for an appointment at a clinic specializing in metabolic disorders. Billy and Christopher have been tentatively diagnosed with Leigh disease.*

*Despite being a bit young for a license, three-and-a-half-year-old **Matthew Scott Newquist** loves to "drive" just about anything—like this tractor at a friend's house. His imagination and infectious laugh have earned him the nickname "Charmer." Matthew, who lives in Big Creek, California with parents Mark and Lisa, has cerebral palsy.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

888

Back and forth, in and out of conventional hospitals and treatment programs. Because complex behavioral issues frustrate treatment of a young child's neurological deficits. Our unique medical and behavioral approach can break the cycle of multiple failures.

C U M B E R L A N D

Hospital for Children and Adolescents • 9407 Cumberland Road • New Kent, Virginia 23124 • 1-800-368-3472

Circle # 18

A Few Miles on the Ol' Rocker

by Edward Sample

Admittedly fearful of speaking in public, Edward Sample of Janesville, Wisconsin chose to vocalize his thoughts as his wife, Roberta, wrote them down.

Most of you have met someone like me. I was the boy in your class at school who you thought never knew the answer.
When the teacher called on me, I cleared my throat and squirmed, but never could answer.
Until the third grade, I knew the answers, and until the third grade, my teachers called on me.
But in third grade, a label appeared on the bottom of my school record.
After that the teacher stopped calling on me.
She stopped dropping by my desk to show me how to do things.
I could still answer the questions, but I couldn't do most of my homework. I couldn't read.
I never understood what happened in the third grade. For a long time, I thought the teacher just didn't like me.
Then I saw my school record. I read the label—I knew why she stopped working with me.

Edward and Roberta Sample celebrated their 25th anniversary in August at the Free Methodist Church in their hometown of Janesville, Wisconsin. Helping to mark the silver anniversary were their children, [from left to right] "Little Ed" and twins, Robbie and Sarah.

I didn't finish high school, but I did learn to read.
I taught myself with the help of a doctor that I worked for while I was in the Army.
Now, I can read, but I still have trouble reading out loud.
I still stumble over words, so I write my words down.
Even if I cannot speak, you will have my thoughts because Roberta said, "Just share what it is like for you. Tell them what it is like to be Dad when your children have some special needs."

I can't really tell you anything about what medical people call "special" about my children.
The children have "cerebral palsy."
I don't know what that means in medical terms.
But I do know what that means to Dad.

It means that some people see me and my family with a label.
It means that some people only see what is "wrong" with my children.
It means that some people only get excited if they think they can "fix" what is wrong.
It means that some people want to know why the children are broken, who broke them and how to get me to do something called "accept."
It means that some people get the words "accept" and "give up" confused.
It means that things really haven't changed very much since I was in third grade. And it means that some people make me mad as hell!

If you look at us this way you are going to miss my real family.
You'll never hear the children laugh.
You'll never see us go to the park to fly our kites.
You'll miss seeing my wife trying to mount a horse—from the wrong side.

Being Dad is pretty much the same for me as it is for any other Dad I know.
I love my children.
I want the best for them.
They make me laugh, and sometimes they make my cry.
"Disability" is not what we are or who we are.
Disabilities for us are just like… having blue eyes, brown hair or freckles.

One advantage of being Dad is nobody expects to see much of you.
I remember the first time my wife and I took Edward to a place that examines slow babies.

890

They schedule appointments 9 a.m. to 5 p.m., Monday through Friday. I took the day off from work.
I drove.
I parked the car.
I carried the diaper bag.
I went and got the parking sticker.
I walked back to the car and put the sticker in the window.
I gave the insurance information.
I signed the forms, and then I went to look for my family.
By the time I found them, the examination was over.
All of the people who had examined my son came into the room to tell what they had found.
They asked my wife the questions, even though I was the one who had taken "maternity leave."
Since I was the one who had been feeding him, I told them it took 45 minutes to give him two ounces.
I told them that he choked a lot on his milk.
The one lady said, "We found nothing wrong."
The doctor said, "Have your wife show you how to hold him."
Several days later someone called for more information...
They asked to speak to my wife.

Most dads I know are in pretty much the same boat.
What is different for me is that special needs do not go away.
There are more and more appointments.
More and more strangers digging in your life.
More and more labels for your child and your family.
Then one day the boss says, "Listen fella, I'm sorry for your problems, but
I can't keep giving you days off."
Even when the boss is understanding, bill collectors are not.
So one day—I don't remember when—
I stopped going to appointments.
I didn't understand much of what was said.
Most of the words—like "fine motor" and "gross motor"—were foreign to me.
Now I know this was the beginning of our family's long, slow process of drifting apart.
One day I realized that mother and children were living one life, and I was living another.
Grown-up men are not supposed to say how afraid they are.
So I watched my wife grow more distant,
more irritable,
more tired.

The Sample children enjoy a crisp autumn day in 1986. [From left to right] Five-year-old Ed and 18-month-old twins Sarah and Robbie.

I never told her how lonely I was.
I never told her how worried about the bills I was, but I nagged about the wash being stacked up, the house being messy and her never having time for me.
I nagged until she cried.
Then I left...

I am ashamed of having left my family.
Every time I left them, I knew it wouldn't help.
All the time I was gone, I loved them and supported them and knew I would come back.
But still I left—until the last time.
As I was putting my things in the car, I overheard my eight-year-old screaming.
"Please God, my Dad, him's leaving cause my brain's broke."
I held him in my arms.
We both cried.
Mom and Sarah joined us.
We were all wrapped up in our sadness.
Then Robbie asked, "Did our dog die?"
There's laughter in our family, too—lots of it.

For too long I sat quietly in the third grade.
My thoughts and feelings trapped inside me.
My son's fear, my family's tears helped change that.
This family is the best thing in my life.
Each of us is of equal worth and importance.
Each of us will share in the other's life.
Because we want to and we need to.

I keep reading that there are very few fathers involved in their children's programs.
Everybody seems to think this is some great new event.
That dads are somehow not interested in their children.
I cannot speak for all dads, but if I had the chance...
I would ask the dads who are doing some of that research to take a look at their own lives.
How many of them visit the doctor with their children?
How many of them could take four days a month off from work?
How many of them can visit their child's program each day?
Does not being there, not knowing, have anything to do with the kind of dad they are?
No.
And it doesn't for me either!
I hope that someday the people who are looking for us dads will remember where many of us have to be.
If you want to see us, you only need to make it possible for us to be a part of our family, without letting our family down.

891

Exceptional Programs For Exceptional Children.

At St. Coletta Schools we believe life is what happens today. Our goal is to provide the best possible life experience for your exceptional child. Students here are not only preparing for tomorrow, they are living quality lives everyday. Founded in 1947, St. Coletta Schools offer a wide range of programs for children with mild to severe developmental disabilities. Twelve-month residential and day programs for ages 6-22.

- Extensive Vocational Training
- Functional Academics
- Community Skills Training
- Daily Living & Social Skills
- Adapted Phys. Ed. & Recreation Activity Program
- Special Olympics
- Behavior Management
- Physical & Occupational Therapy
- Speech Therapy
- Music, Art & Computers
- Prader-Willi Program

St. Coletta's
OF MASSACHUSETTS
John W. Shyne, Jr., President

Cardinal Cushing School & Training Center
400 Washington Street, Hanover, MA 02339
Braintree St. Coletta Day School
85 Washington Street, Braintree, MA 02184
Contact: Lynne Goyuk
Tel: (617) 826-6371
Fax:(617) 826-6474
Sponsored by
The Sisters of St. Francis of Assisi of Milwaukee, WI

Circle # 73

Did I Hear You Say Help?

National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

- ☐ Are you looking for appropriate services for yourself, your family member or client?
- ☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline 1-800-369-INFO.

We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle # 173

You need to find us soon.
If you wait too long, the reason you need to find us may have already separated us from our family.
You can find me,
early mornings,
evenings,
weekends and holidays.
I have 10 sick days a year and two weeks of vacation.
Nothing—absolutely nothing—is more important than my family.
But in addition to their "special needs," they need a place to live, food, clothing, transportation.
Sometimes I even waste a few dollars on things they want.
I like being Dad. I need to be part of my family.
I used to accept being the "missing father."
Not anymore.
I may not know all those fancy words on those evaluations.
But I've put a few miles on the ol' rocker with all three children.

I am part of what keeps my family healthy.
We depend on each other.
So, the next time the phone rings at my house and it is someone needing information about one of my children,
I hope they won't ask for my wife.
But if they do,
I want to be strong enough to tell them...
"This is their Dad. I can help you."

Edward Sample, 53, retired three years ago after 30 years with General Motors Corp. He now works full-time doing maintenance for the First Lutheran Church in Janesville, Wisconsin. Edward lives in Janesville with his wife, Roberta, and their children, Edward Jr., 13, and nine-year-old twins Sarah and Robert. All three children have cerebral palsy. This piece was first published in the National Fathers' Network's NEWSLETTER, *Summer, 1992.*

***Fathers' Voices** is a regular feature of* EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

892

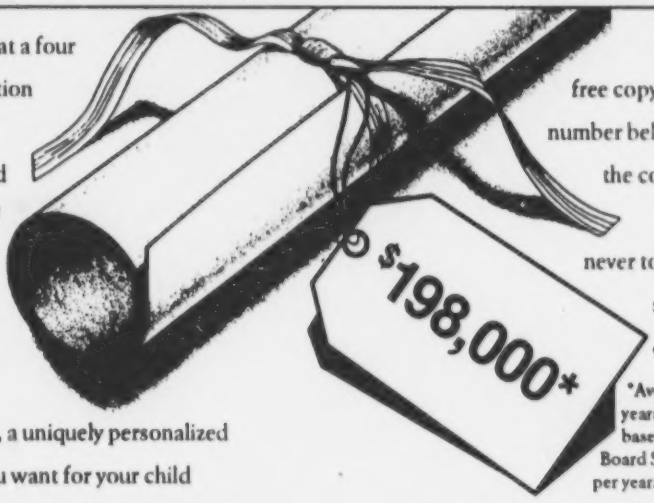
Invest in your child's future now so you can pay for it later.

The CollegeBuilder® Program Free from Merrill Lynch.

$198,000* That's what a four year private college education could cost sixteen years from now. So if your child is likely to be a member of the class of 2006, it's not too early to start saving.

To help you, Merrill Lynch has created the CollegeBuilder® Program, a uniquely personalized analysis based on what you want for your child tomorrow and what you can afford to put away today. Your Merrill Lynch Financial Consultant can help you map out strategies to help meet your family's goals. And, through tax-favored investing, you may be able to minimize the tax bite on your child's college savings.

It's all explained in the CollegeBuilder® Program Brochure.



To receive your free copy, simply call the number below. Or just mail the coupon.

Do it today. It's never too early to start saving for your child's future.

*Average costs for four years of private college are based on the 1989-90 College Board Survey using a 7% increase per year.

1-800-765-4833 TTY, ext. 8769

If you are hard-of-hearing, you can call 1-800-765-4HOH, ext. 8769

Mail to: Merrill Lynch Response Center
P.O. Box 30200, New Brunswick, NJ 08989-0200

☐ Please send me a free copy of *CollegeBuilder Program* brochure.

Name _____ Address _____

Business Phone _____ City _____

Home Phone _____ State _____ Zip _____

Merrill Lynch clients, please give name and office address of your Financial Consultant: _____

8769

Merrill Lynch
A tradition of trust.

©1994 Merrill Lynch, Pierce, Fenner & Smith Inc. Member SIPC.

Circle # 188 893

RELIGIOUS PARTICI

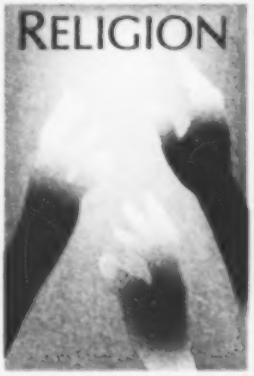
Creating stories we can celebrate

by Bill Gaventa

"Tell me your church and synagogue stories."

I'll never forget the answers I got the first time I asked that question at a relatively large gathering of parents and advocates. This was in the late '80s, at a South Carolina conference for parents of children with Down syndrome.

One mother told me she and her husband had used their congregation as an arena where their daughter could begin to develop her own sense of identity and independence. The parents trusted their church community enough that they could, as the mother said, start letting go. Now a young adult, their daughter lives in a supported apartment.



Another said, "We took our minister to our IEP meeting at the school. It was wonderful. We got everything we wanted."

After a pause she added, "They thought he was our lawyer."

Everyone laughed, but the point was made. Think what could happen if clergy or congregational advocates regularly went with families as supports and friends during what can be very anxious planning times.

The discussion reminded me of one of those times—16 years earlier—when I sat with an interdisciplinary diagnostic team in North Carolina as they tried to figure out where a young boy with developmental disabilities could get some desperately needed socialization and recreational experiences. Though this rural area of the state had few specialized programs, an obvious possibility was a community in which the rest of the family was involved—their church and its Sunday school. However, as a young chaplain-in-training, I was too intimidated by all the discussions of highly professional diagnostic tests and interviews to mention the family's church as a possible resource.

Unique opportunities

Today, however, many parents, professionals and religious leaders realize that religious education and congregational life offers unique and wonderful opportunities for children with disabilities. Besides giving children an opportunity to learn and grow in their faith tradition, participation in congregational life may allow them to realize that they, too, are part of God's people with gifts to be celebrated and needs to be shared.

What's changed? Along with shifts in public education and systems of care, the International Year of the Disabled in 1980 and the Americans With Disabilities Act in 1992, religious denominations and faith groups have developed a number of resources to stimulate and encourage congregational inclusion of children and adults with disabilities. Almost every faith group now has an office which deals with religious education and ministries with people with disabilities, either on a full- or part-time basis. Interfaith networks and programs connect many others, and share resources through magazines, newsletters or journals. Models of congregational ministry and services include both specialized and inclusive religious education programs, creative ways to facilitate participation in worship, congregational respite care, group homes run by religious groups, disability awareness materials, daycare, camps and congregation-based circles of support.

The resources and models are there, although finding them may require looking beyond the boundaries of your own denomination, faith tradition or local religious bookstore. Learning about services provided by other faith groups can lead you to ask one of the most effective questions for initiating new congregational awareness and inclusiveness—"If they can do it, why can't we?"

Congregation benefits

But tapping the potential in congregational supports also means taking a hard look at the painful experiences of families and people with disabilities when the doors to their congregations seem to close. Many recent studies have testified to the importance of personal faith and spirituality in sustaining parents and families of children with disabilities. But when these same families were asked if they had received much support from their congregations, most gave answers of "no" or "very limited."

These studies come alive when we listen to families share their own individual stories—stories that can compel congregational change. One mother told me about her family's efforts to find a new church home after a move from out of state. They tried including their daughter—labeled "moderately retarded" and "microcephalic"—in a church youth group without advance preparations. Someone in the group said something that hurt the girl's feelings, and she refused to go back to church. The mother admonished her daughter that the church was God's

894

PATION FOR ALL

house and that, as a family, they needed to be there. Her daughter listened to this explanation, then said simply, "Well, it may be God's house, but He's not home."

The loss in these stories is not just to the family and the child, but also to the congregations. Many congregations who have worked to include children and adults with disabilities will testify to their belief that in the long run, the congregation is the greatest beneficiary of the experience.

Creating stories to celebrate

What needs to happen now, so more of these stories become stories we can celebrate? Challenges and opportunities exist on many levels:

- Families, parents and people with disabilities need to knock on the door of their faith community—sometimes with others acting as advocates or guides on their behalf—with resources, models, hopes and needs in hand.
- Clergy and congregations need a vision of hospitality, a commitment to the importance of including every individual and his or her gifts, the wisdom to know that it takes time to build trust, understanding that the first prayers may be ones of lament or anger and an awareness that an effort to include one person or family will touch many people. And they need to know that they do not have to become a special educator in order to help. They simply need to let families know that they are welcome in that place called a "sanctuary," and that God is home.
- Professionals and advocates can use their understand-

ANDREAS YUAN

"Please don't bring Andreas to Special Religious Education anymore."

I heard the words in dismay. Although he was 15 years old, my son was preparing for First Communion.

"Andreas' volunteer teacher is all right with him, but the other teachers in the group have said they will quit if he doesn't stop coming."

The week before, Andreas had taken me by the hand and quietly led me into the special prayer room. With a sense of awe, he'd taken me up to the altar to show me the candles and Bible.

"The real reason is, he's disruptive of our process of coming closer to God."

It took me several months to get over my hurt and bitterness. In the end, it was Andreas' eagerness to go to church that led me back. Although he couldn't speak, whenever we passed a church, Andreas would wave his hand back and forth in his own sign for singing. This time, however, I approached our own parish in the town where Andreas was fully included in high school.

Immediately, a group formed to prepare Andreas. It included one of his high school classmates, our priest, the director of religious education and several other members of the congregation. Every Sunday, we stayed after the service and had a "mini-Mass" with Andreas. We explained each part repeatedly and practiced receiving communion. Following the consecration of the bread and wine, Andreas would shout out in acclamation. These shouts had become so much a part of the Mass that the priest normally waited for them before continuing the service.

Our biggest stumbling block was the texture of the host (unleavened bread). Like many people with autism, Andreas is very sensitive to texture—and he had decided this was *not* his idea of bread! One week, we brought a bag of unconsecrated hosts home to give Andreas some time to get used to the texture. Later, when I discovered the bag missing, I found Andreas very solemnly putting host after host on the outstretched tongue of the family dog!

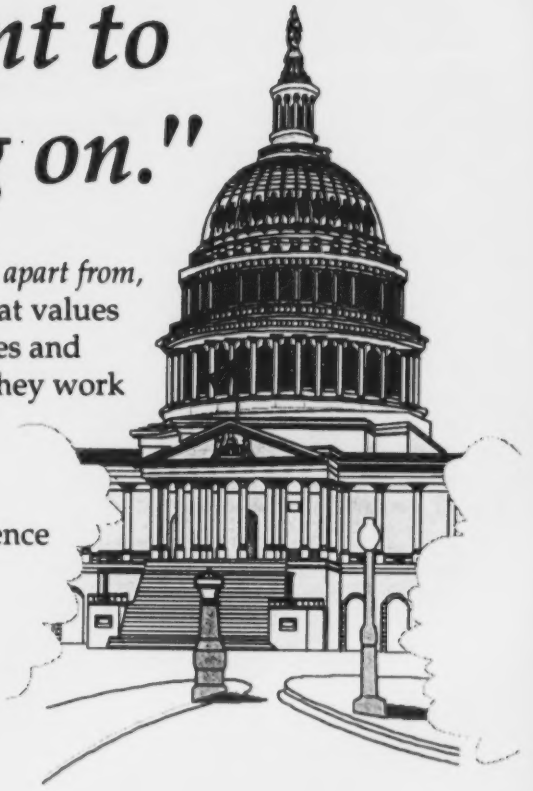
Finally, the big day arrived. His sisters came home from their distant colleges; a close family friend, who happens to be Jewish, also attended the service. When the big moment arrived, Andreas walked to the front of the sanctuary, surrounded by his entourage of family and friends. Suddenly he realized someone was missing! Andreas returned to our pew and taking our Jewish friend by the arm, brought him forward to join the group. Then Andreas opened his mouth and happily ate the host. The congregation erupted in cheers! Andreas belonged—and we all came closer to God, together.

—Susan Yuan

Andreas Yuan (second from right) celebrates his first communion at St. Thomas Church in Underhill, Vermont with (from left to right) family friend Eric Adler, sisters Semele and Elena Yuan, Father Francis Prive, mom Susan and high school classmate and friend Christopher Kellner.

895

"As a parent, I want to know what's going on."



If you believe that all people should be *a part of,* and not *apart from,* the rest of your community...if you believe in a world that values what each person contributes...if you believe that families and people with disabilities can get better representation if they work together for change...

Work with **United Cerebral Palsy Associations** in influencing the new Congress to advance the independence of people with disabilities.

Fill out the form below to become a part of our *national grassroots effort.*

Your voice can make a difference.

❒ Yes, I want to know what's really going on. I particularly want to become involved in issues related to the following area(s):

- ❒ Early Intervention/Infants & Toddlers Programs
- ❒ Education/Special Education
- ❒ Transition from school to work
- ❒ Social Security for kids/adults
- ❒ Employment/Rehabilitation
- ❒ Transportation
- ❒ Housing/Home Ownership/HomeModification
- ❒ Aging with a disability
- ❒ Civil Rights (Americans with Disabilities Act)
- ❒ Personal Assistance Services
- ❒ Family Support - keeping your child at home and your family together
- ❒ Telecommunications (using the information superhighway)
- ❒ Technology (wheelchairs, computers, communication devices)
- ❒ Impact of health care reform on people with disabilities and their families
- ❒ Other, please specify:_____

Name: _____

Address: _____

Phone: _____

Fax: _____

Age of family member with disability:_____

Please mail this form to: United Cerebral Palsy Associations, Governmental Activities Department, 1522 K Street, NW, Suite 1112, Washington, DC 20005 or fax it to (202) 842-3519.

ucpa *Advancing the independence of people with disabilities*

ing and skills in direct ways in congregational settings, but they should also realize that they can teach and guide others. Just as a job coach facilitates integrated employment, we need more people willing to be "church and synagogue coaches"—people who believe in and are able to tap an existing reservoir of good will and desire to help.

It's important to realize that a congregation's initial effort can focus on the life of one child and one family.

• Everyone needs to realize that a church or synagogue can take the first steps without starting a formal "ministry" or "program." Often, specialized programs are the established way of doing things, but it's important to realize that a congregation's initial effort can focus on the life of one child and one family.

Telling our stories

In the pages of this issue, you will hear about some national and local efforts, see some of the resources and feel some of the faith, hope, pain, and love. And in the months ahead, *Exceptional Parent* has expressed its willingness to host a dialogue between families and religious leaders in many traditions through occasional articles.

So what are your stories? What's worked for your family in your faith tradition? What hasn't? Write to me in care of *Exceptional Parent* (209 Harvard St., Ste. 303, Brookline, MA 02146). Help us tell the stories!

Bill Gaventa is an ordained American Baptist clergyman and chaplain. Since 1973, he has been involved in ministries involving people with developmental disabilities and their families. He currently serves as director of Community Training and coordinator of Congregational Supports for the University Affiliated Program of New Jersey. He lives in Princeton, New Jersey with his wife, Beverly, an associate professor at Princeton Theological Seminary, and their son, Matthew, a high school student.

VERONICA CHLOE

When Veronica Chloe played an angel during a Christmas play at the Ebenezer African Methodist Episcopal (AME) Church in Fort Washington, Maryland two years ago, Christmas took on a new meaning for many—especially her mother, Sandral. For her, Veronica became the perfect image of an angel, Sandral recalls.

Seven-year-old Veronica, who has cerebral palsy, was three years old when the church began its Exceptional Child Ministry, a program for children with disabilities. Sunday school classes are the primary focus of the program, but it also offers opportunities to participate in social activities like movie nights, monthly outings and the Christmas play.

In Sunday school, children with disabilities study the same curriculum as other children in the church. However, they are taught at their own pace and in whatever format is necessary, including Braille and sign language. After each class, the children join the rest of the congregation for worship in the sanctuary.

Veronica, one of the program's original participants, has benefited greatly from the socialization opportunities church activities have provided. Easily startled as an infant, Veronica has grown so accustomed to the singing and clapping of hands in worship service that she no longer jumps at sharp noises. This has also affected her behavior outside of church.

"Veronica is a very sociable child," says Sandral. "She is very attentive to the ministers and perks up when she hears their voices on the radio." Veronica also becomes noticeably animated when the congregation begins singing The Lord's Prayer, a prayer she knows and loves.

Marion Crayton, president of the Exceptional Child Ministry, says when you "come into Veronica's presence, something happens. She has a radiance around her."

Veronica's "gift of smile," her mother says, has garnered many new friends and won the hearts of her pastors and congregation.

—Jennifer M. Koerber

897

CATHOLIC LIFE FOR CHILDREN WITH DISABILITIES

by Marilyn E. Bishop

Just ten years ago, Catholic parishes tended to come up with quick solutions when a child was diagnosed with a disability involving learning deficits. The child's parents were either advised that their child was an angel and did not need the saving grace of the church's sacraments, or they were told that a separate class or tutor could prepare the youngster for receiving eucharist (communion) or confirmation. Today the picture is very different.

Sometimes a child with a disability is included in regular religious education classes without obvious modifications. In California, Mary Brosseau, director of the Department for Special Religious Education, surveyed 44 parishes and discovered that "common sense" was the primary method used for including children. "In speaking with directors of religious education, I have found that many do not realize the level of assistance that they are providing because it simply seems common sense," Brosseau said in her newsletter, *News Notes from the Department for Special Religious Education.* "In other words, they are doing a better job at making adaptations than they realize."

In other parishes, the welcome mat for children with disabilities is more organized and deliberate. At St. Luke Church near Dayton, Ohio, the catechists (Sunday school teachers) were trained in curriculum adaptation and cooperative learning techniques. The teachers were told that the learning goals were not the same for everyone, but that all the children would discover that community means that *all* belong.

And when the child is accepted, his or her family feels that same welcome. "Our family was now a part of a bigger family," said Debbie Pollard, whose children—one

GIDEON GOLDSTEIN

Having Prader-Willi syndrome means always resisting the urge to eat what's in front of you. Keeping Kosher requires the same type of resistance to eating without restriction and thoughtful consideration. For Gideon Goldstein, each set of dietary rules reinforces the other.

Gideon, 14, is a high school freshman whose command of the Hebrew language is remarkable. While he may struggle with math assignments and physical education classes, Gideon is always welcomed as a full participant in the Orthodox Jewish "minyan" (prayer group). In this setting, Gideon is not viewed as a teen struggling with the challenges of his disability, but as a young man who often provides the obligatory "tenth man" needed to begin morning prayers. Faced with fine motor problems that make writing a frustrating exercise, Gideon is able to manage the intricacies of "laying tefillin" (see photo) in preparation for prayer, winding the leather straps in a specific pattern around his hand and arm and wrapping another strap and box across his forehead.

In 1985, Gideon became one of the charter members of a new special education program at Temple Chai religious school in Phoenix, Arizona where he received an individualized program of Judaic and Hebrew instruction in both resource and regular classes. When he stood before the congregation for his bar mitzvah, the glow of his pride and happiness transformed the sanctuary. No one who attended will ever forget that service.

Part of a close and loving family, Gideon enjoys reading, music, animals and attending sporting events. As traditional observant Jews, his family spends Shabbat (the Sabbath) together in prayer and study. Gideon relishes this weekly escape from daily stresses that have accompanied his entrance into high school. Parents David and Carol and younger brother Noah also find great joy in this day of rest when labels like "able" and "disabled" disappear, and each family member comes together to share equally in the study of Torah (the scriptures).

Gideon Goldstein begins each day with the morning davening (prayer).

—*Becca Hornstein*

with spina bifida and one with cerebral palsy—were included in a regular weekly religion class at St. Luke. When Debbie's daughter, Megan, was hospitalized at Christmas time, she was eager to return home—not to play with her toys—but to go to church. Megan told the doctor, "I have to go home because tomorrow is church."

Debbie believes that Megan's positive experience with the church is important for her future. "That will see her through the trials she's got ahead of her in life," she said.

Parish advocates

It would be inaccurate to imply that Catholic students with disabilities have no barriers to enrollment in religious education. For example, one priest declared such training unnecessary for Claire, who is deaf, blind and mentally retarded. But her mother insisted that Claire could benefit from sacramental preparation. The director of religious education agreed and located a tutor from the

The learning goals are not the same for everyone, but all the children discover that community means that all belong.

nearby Catholic university, the University of Dayton. With support from the university's Center for Ministry with Disabled People, the tutor was trained to successfully instruct Claire. Such staff support is provided in various ways in different parts of the country.

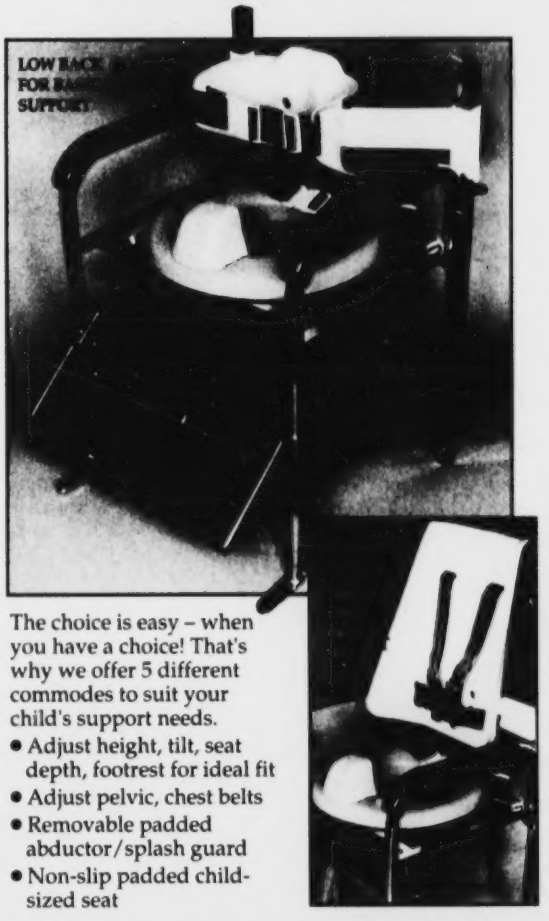
In the Archdiocese of Boston, for example, people with disabilities are identified and supported by "parish advocates." Of the 400 parishes in this archdiocese, 75 have trained people to provide resources and support to adults and children with disabilities. Pat Friel, director of the Office for Persons with Disabilities for the Boston archdiocese, is concerned with making people with disabilities feel welcome in local churches. "How do we word our invitation to welcome children with disabilities? How do we teach the appropriate response to pastoral care needs?" she asked. Her answer was to initiate a 30-hour certification course to provide volunteers with information about communication skills, various disabilities and advocacy techniques. (Training materials are available. For more information, contact the Office for Persons with Disabilities, Archdiocese of Boston, 240 Adams St., Dochester, MA 02122, 617/254-0100.)

Inclusive parochial schools

One of the needs a parish advocate may discover is the desire to enroll a child with disabilities in the regular parish parochial school. "The calls that are most disturbing to me are the calls I get from parents whose children are rejected by parish schools because those schools have not thought of ways to include all children," said Mary

Comfortable, secure support anywhere!

Use the Columbia Positioning Commode freestanding or over any toilet



The choice is easy – when you have a choice! That's why we offer 5 different commodes to suit your child's support needs.

- Adjust height, tilt, seat depth, footrest for ideal fit
- Adjust pelvic, chest belts
- Removable padded abductor/splash guard
- Non-slip padded child-sized seat

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 13

Jane Owen, director of the National Catholic Office for Persons with Disabilities in Washington, DC. A common reason for denying admission to a student with a disability is that the educational needs of the student demand resources—especially financial resources—that the school does not have.

Owen believes parents may need to pursue legal means for helping their parish schools get the money necessary to serve students with disabilities. She cites the precedent-setting 1993 Supreme Court decision in the Zobrest case as hopeful. This decision declared that public funds could be used to pay for interpreter services for a deaf student attending a Catholic high school. The important issue in this case was that the child—rather than the school—was the recipient of the services paid for with public funds.

But funding is not the only issue. Like many public school teachers, Catholic school teachers often feel their skills are inadequate to teach children with learning differences. The newly-formed Network of Inclusive Catholic Educators at the University of Dayton is allaying those anxieties by training teachers to use alternative strategies like cooperative education, curriculum modifications, peer tutoring and teacher-to-teacher mentoring. The network hopes to begin using computers to share information among educators and professionals as the number of inclusive schools grows beyond the 30 currently identified.

This movement toward inclusive Catholic schools is encouraged by the National Catholic Educational Association (NCEA). In 1995, NCEA's national convention will offer at least three workshops on inclusion.

A nudge and some guidance

The policy of the Catholic church is inclusive. But, as Mary Jane Owen aptly described the situation, "The words are there, but the actions do not always follow the words." The guidelines on page 33 ("Advocating for Access") offer parents some pointers on helping their church communities become more accessible. Though more and more churches are making efforts to welcome all to their community, some may need a nudge and some guidance to set the wheels in motion.

Marilyn E. Bishop is the director of the Center for Ministry with Disabled People at the University of Dayton. She established the center in 1980. The purpose of the center is to link the resources of the university with people who have disabilities to support their spiritual enrichment. Marilyn has a B.A. in communication and is an M.A. candidate in religious studies.

We Can Make A Difference!

"Now I can see my beautiful daughter flourishing and making progress that I never thought possible! Thank goodness for a place like this school."

-Parent

Intensive Program

When you feel that there isn't any answer, when you feel there are no other options available, **DON'T GIVE UP!** Our Intensive Program makes a difference for students with serious, challenging behaviors.

We accept students with **Autism, Mental Retardation and Behavior Disorders** who require the specialized care that other schools just cannot provide. We give our students state-of-the-art educational and residential programs free of painful aversives and excessive medication.

Many of our students arrive at **The New England Center for Autism** after having had a long history of rejection and failure. With us they receive intensive, positive, behaviorally oriented treatment that focuses on developing the coping skills and appropriate behaviors which enable them to live and work successfully with minimum support. Intensive Program students participate in the full range of academic, community, and recreational activities provided for all of our students.

*Let **The New England Center for Autism** make a positive difference in your child's life.*

Serving children and adolescents with Behavior Disorders, Mental Retardation, and Autism.

For more information on our Intensive Program, please contact **Catherine M. Welch, MEd, Director of Admissions.**

The New England Center For Autism

The New England Center for Autism
33 Turnpike Road,
Southboro, MA 01772
(508) 481-1015
Just 20 miles from Boston

Circle # 171

900

A JEWISH EDUCATION FOR EVERY CHILD

by Becca Hornstein

"Educate each child according to his ability." —Proverbs 22:6

I just wanted what any Jewish mother wants for her son—I wanted Joel to have a bar mitzvah. The problem was that Joel has autism and in 1983, most religious schools made no accommodations for children with significant learning difficulties.

On the face of it, my desire for Joel to have a Jewish education may have seemed preposterous. Joel had lost the little bit of spoken language he had possessed when his autism surfaced at 21 months. A self-taught reader, Joel could read and write by his second birthday and quickly learned sign language, too. But he didn't begin to verbalize phrases until age eight. Why, then, was I pursuing a goal which would require years of study in both English and Hebrew and would culminate in Joel speaking before a sanctuary filled with people?

As any parent of a child with a severe disability knows, the diagnosis of a child's disability creates a tremendous sense of isolation, along with sporadic anger and grief. For many, the logical source of comfort and renewal is within one's religious community. Although I had wrestled with my own anger at G-d* when Joel was diagnosed, by the time he was nine years old, I had made my peace and craved the support, warmth and spiritual renewal of my religion. My desire for Joel to prepare for a bar mitzvah was part of the healing process. I wanted to be able to formally declare to family and friends that Joel was a person of value and dignity, an asset to his community and a blessing to his congregation. Most importantly, I wanted Joel to know he was accepted by his fellow Jews.

Responding to parents' requests

Jews have been referred to as "the people of the Book." But what can they offer to the child who cannot read, hold or see the Book? Presented with children or adults who had developmental, communicative and learning disabilities, rabbis of the past centuries were at a loss. Communities provided for the safety and welfare of Jews with special needs, but formal religious instruction could not take place until new systems of adapting teaching materials and methods were developed.

In the late 1970's, as federal legislation began to change the face of public school education for children with special needs, Jewish educators began to respond to parents' requests for religious education, like mine for my son, Joel. Until the mid-1980's, very little was available outside of New York City, where Orthodox Jewish communities had already instituted some special classes and schools. At that time, the Coalition for the Advancement of Jewish Education began to offer teacher training workshops at their annual national conferences. The Conservative and Reform movements began to look at curriculum modifications, disability-sensitivity workshops and ways of creating a network for families who have children with special needs.

In 1985, the Reform movement held the first national conference on special needs and began publishing the *Liheyot Connection*, a national newsletter devoted to disability issues. In the Orthodox community, the Otsar (meaning "treasure") organization was founded by parents of children with diverse developmental disabilities to provide educational and recreational programs for people of all ages.

Exciting opportunities

Without a lot of fanfare, Jewish special educators began creating exciting opportunities for children, teens and young adults with mild to severe disabilities. In Chicago, the Keshet program initiated a wide variety of programs, including a Sunday school which now has a dozen classes with a high staff-to-student ratio and individualized experiential curriculum. For day school students, Keshet provides a special education program on four regular Jewish day school campuses. This affords students some integrated classes in addition to specialized Judaic and non-religious studies. By using volunteers in both classrooms and recreational activities, Keshet continues to provide disability awareness in the community.

Other Jewish communities—including those in Akron, Houston and San Francisco—employ a special education consultant who visits day and after-school religious education programs to provide teacher training, classroom observation, curriculum modification and behavior management techniques. With this assistance, religious schools can offer inclusion to many students with significant learning differences.

Self-contained Jewish day schools for children with mental and physical disabilities are unusual outside cities with large Jewish populations. However, good examples can be found in Baltimore's Gesher Latorah and greater Washington, DC's Shema V'Ezer schools. Whenever possible, students attending these schools are integrated with students in nearby Jewish day schools.

Many religious schools have added resource rooms for children having difficulty in learning to read or write Hebrew. Some religious schools, like Temple Chai in

*The author of this article follows the Jewish prohibition against writing the full name of G-d.

901

EYAL SHERMAN

When Eyal David Sherman took the pulpit on the Saturday morning of his bar mitzvah, read from the Torah (scriptures) and led the prayers, the congregation heard him—silent and clear.

Nearly 1,000 worshippers at Temple Adath Yeshurun in Syracuse, New York, read Eyal's lips as video cameras projected the text and his face onto large screens mounted at the front of the sanctuary.

"Even though my bar mitzvah is different or awesome or radical, being high tech, I never really thought about that," Eyal said in his speech. "I just knew that when I reached age 13, I'd be up here on the bimah (pulpit) and have a bar mitzvah just like any other kid."

Nine years ago, Eyal suffered a stroke after surgery for a brain stem tumor. It left him a quadriplegic who—technically speaking—cannot walk, talk, breathe or eat "on his own." But that's not how Eyal sees it.

That Saturday, in front of the doctors and nurses who saved his life; the public school-teachers who helped bring him into regular classrooms; his mother, Leah, who first began teaching him Hebrew at home and his father Rabbi Charles Sherman, the spiritual leader of the congregation, Eyal performed the ritual marking him an adult in the Jewish community. And being an adult, he said, means "taking responsibility" for your own life.

After Eyal's bar mitzvah, a woman whose son has a neurological disorder, told Rabbi Sherman, "Now I know my son can have one, too." A public bar mitzvah sends a message to children with disabilities that "you're not shunned; you're not isolated," said the rabbi, who believes it is the clergy's moral obligation to give every child a religious education according to his or her abilities and a chance for religious expression in his or her own voice.

In his silent voice, Eyal gave a message of his own back to his community. As his father explained, "With all the horrible things in this life and all there is to complain about, you see that a kid can still ascend the pulpit and thank God for what he has."

—Andrea Kamens

[Above] Eyal Sherman rehearses for his bar mitzvah with his teacher, cantor Emanuel Perlman, and mother, Leah. Photo: Dick Blume. [Left] Eyal plays the electric drums, providing some of the entertainment at the party following his bar mitzvah ceremony.

Phoenix, have developed a continuum of educational options ranging from small self-contained classes, to pull-out, resource-room Hebrew classes, to inclusion with or without one-on-one assistance.

Since learning is a lifelong experience, programs such as Chaverim in greater Los Angeles offer a wide variety of classes as well as social and recreational activities for adults with disabilities. Their annual retreat now draws participants from as far away as San Francisco.

Bar mitzvah boy

Joel will soon be 21 years old. After several years in Temple Chai's self-contained class, he stood before 200 people for his bar mitzvah in May, 1987. Joel led the congregation in prayer and chanted his Torah portion (selection from one of the first five books of the Hebrew scriptures) and Haftarah portion (selection from the Prophets). On that day, surrounded by family and friends, teachers and classmates, Joel was special—no, not "special needs" and not "special education"—Joel was special because he was the bar mitzvah boy. His achievement reflects the rapid growth of Jewish special education and the benefits it has brought to both families and congregations.

Becca Hornstein is the executive director of the Council For Jews With Special Needs in Phoenix, Arizona. Becca lives in Scottsdale, Arizona with her husband, Barry, an instructor in special education at Glendale Community College, and their two children, Joel and Shana.

902

TOWARD A MORE INCLUSIVE PROTESTANT SUNDAY SCHOOL

Making religious education accessible to all

by Brett Webb-Mitchell

This is a story of a good struggle that led to new ways for children with disabilities to be included in a Sunday school program in an East Coast, suburban, Protestant church. For a time, this church was the scene of a struggle. On one side of the debate were parents of children with disabilities, who wanted them included in regular Sunday school classes. On the other side were parents of children without disabilities, who disagreed.

After many months, the stalemate was unexpectedly broken by something the *children* did—someone finally noticed that when the children with disabilities and the children without disabilities shared time together on the church's playground, the atmosphere was one of mutual caring and fun. On that playground, the children played happily together and helped each other enjoy the playground equipment. They were truly living Jesus' commandment to "love your neighbor as yourself."

With the eyes of the congregation now open to the lessons of the children, they were able to appreciate a story shared by one of the Sunday school teachers about Jimmy, an eight-year-old boy with mental retardation. During a Sunday morning worship service at the end of Vacation Bible School, Jimmy had walked to the front of the sanctuary. He wanted to hold the Bible for the worship leader. He wanted to be included in worship—doing something, anything—and his assistance was welcomed.

TYLER HOLGREEN

When Tyler Holgreen was diagnosed as a baby with 49,XXXXY syndrome, a rare variant of Klinefelter syndrome which causes intellectual and physical limitations, doctors said he would probably never participate in the same activities as other kids. At 12 years of age, however, Tyler Holgreen is usually just "one of the gang."

"Oh, the other kids know his problems," says his father, Lynn, "but they work with him and walk him through things."

Things like an after-school game of touch football. Or his responsibilities as a deacon in his Syracuse, Utah congregation of The Church of Jesus Christ of Latter-day Saints. With the church's worldwide educational and ministerial structure comprised entirely of volunteers from local congregations, Tyler's role as a deacon is a significant responsibility.

Tyler Holgreen serves as a deacon in his local congregation of The Church of Jesus Christ of Latter-day Saints. The position is one of significant responsibility and trust for any youngster.

But of greater significance to the church is Tyler himself, says Doug Hind, manager of Special Curriculum at church headquarters in Salt Lake City, Utah. Hind's job is to see that those with disabilities enjoy "the same opportunities for growth, friendship and recognition" as any other member.

The church provides a number of services to give members with disabilities equal access to religious activities and education. Tyler Holgreen, for example, who normally wouldn't begin Seminary—a demanding four-year program of religious study offered to Latter-day Saint youth worldwide—until ninth grade, benefits from a two-year head start for children with disabilities. Tyler's father, Lynn, comments that Tyler often receives one-on-one tutoring from his leaders and his pals—in the chapel and on the line of scrimmage in his neighborhood backyard football "league."

And that's the way it should work, says Lynn—support from church leaders enhanced by individual concern. "These people are very aware," he says. "And they are very willing to help."

—Clayton Newell

903

The congregation was also able to appreciate the abilities of Sandra, a 10-year-old girl with Down syndrome who loves to play with the other children on the playground. She gets all the other children—children with and without disabilities—to participate in the fun and games. The Sunday school teachers call her a "natural leader," as she effortlessly orchestrates playground games that all can enjoy.

This congregation has come to understand that inclusive Sunday school classes give everyone an opportunity to share the God-given gifts of all young church members.

As this congregation began to recognize the potential contributions of children with disabilities, teachers and parents started working on strategies to include all children in the Sunday school program, putting an end to segregated classes. This congregation has come to understand that inclusive Sunday school classes give everyone an opportunity to share the God-given gifts of all young church members.

Segregation and the "public school paradigm"

Gestures of caring, openly practiced by the youngest members of this congregation, helped open a door that had long remained shut. Yet few "mainline" Protestant churches recognize the power of such gestures. Instead, in most Protestant churches, educating children in the Christian faith still means reading, writing and rote memorization of Bible stories, along with group discussions where participation requires a certain level of verbal fluency.

Among religious educators, this method is known as the "public-school paradigm," and like many public schools where children with disabilities are still segregated, many children with disabilities are also kept out of regular Sunday school classes. Many Protestant churches have developed specialized curricula for people with mental retardation or

RYAN REED

As a public school student, Ryan Reed's test results indicated he would never learn to read. He was assigned to classes focusing on non-academic skills.

But Ryan's mother, Mary Jo, believed she could recognize many signs of reading readiness in her son. When public school teachers and administrators refused to modify his educational goals or class placement, she turned to the Catholic school in her parish.

Parochial schools often respond to a request like Mary Jo's by saying, "We can't do what the public schools can. We don't have the money or the resources." But Ryan needed only good teachers and a good learning environment.

This is not to say that Ryan's family or teachers at St. Peter's School in Rockford, Illinois took lightly the inclusion of a child with Down syndrome. There were plenty of skeptics and naysayers. And even those who felt Ryan's inclusion could succeed, recognized the need for careful planning and preparation.

When 11-year-old Ryan entered fifth grade at St. Peter's, he was reading at a pre-primer level. By the end of the school year, he had achieved a second-grade reading level. He entered seventh grade last fall reading third- and fourth-grade materials.

He learned to read from good teachers who used a whole-language approach. He was also helped by classmates who offered models of reading and correct spoken language along with their friendship and encouragement. Most of all, however, Ryan learned to read because he really was ready to learn.

Ryan Reed (back row, center) is a member of the basketball team at St. Peter's School in Rockford, Illinois.

Ryan's inclusion at St. Peter's extends beyond the classroom. He's on the basketball team, in the scout troop and a frequent guest at birthday parties. He is an altar server and has been a prayer leader at Mass.

Now, St. Peter's hardly remembers a time when Ryan wasn't part of the community. When asked recently if she'd do it over again, principal Sister David Ennis replied, "I'd do it again in a minute. Ryan has been a gift to our school. His hunger to learn has inspired us all. His special needs have helped us remember how much we all need. Thanks to him, our school is a better place."

—Margaret R. Bowman

904

other disabilities that may be taught in special classes outside of the "normal" Sunday school program. Many of these same churches go so far as to advocate a separate worship service for people with disabilities.

Toward greater inclusiveness

Even within the structure of most Protestant Sunday school programs, greater awareness and small modifications may allow children with disabilities to be included. Here are some practical suggestions:

• *Teach children about differences.* Invite children and their parents to learn about differences in abilities that may affect what people can and cannot do in church, at home or in the community. Focus on the fact that we all have different abilities and limitations.

• *Focus on what children with disabilities can do.* Let parents and their children with various disabilities teach Sunday school classes what a child with a disability *can* do in the context of church activities. One focus might be on alternative forms of communication—like signing songs, painting responses rather than verbalizing, or dramatizing a Bible verse rather than reading it.

> ***Focus on the fact that we all have different abilities and limitations.***

• *Create a "least-restrictive" Sunday school environment.* Minor modifications—both in the physical layout of a class and the structure of its schedule—can make a Sunday school class more accessible to a child with a disability. If a child is in a wheelchair, the class layout can allow plenty of space for that child to move around. If a child has a visual impairment, someone can be responsible to tell that child about things he or she cannot see. If a child has a hearing impairment, it will be important for the teacher and other students to know the best way to communicate with that child.

Such changes in the Sunday school—even within the limitations of the "public-school paradigm"—can open up doors for people with disabilities to participate. It will also help others to see anew the diversity of gifts in the church.

Brett Webb-Mitchell, a visiting assistant professor in Christian Nurture at Duke Divinity School, is also the president of the Religion Division of the American Association on Mental Retardation. He is the author of GOD PLAYS PIANO, TOO: THE SPIRITUAL LIVES OF DISABLED CHILDREN *and* UNEXPECTED BANQUET: WELCOMING PEOPLE WITH DISABILITIES INTO THE CHURCH, *both published by the Crossroads Publishing Company.*

ADVOCATING FOR ACCESS

by Marilyn Bishop

Parents have long been the prophets and organizers for education, services and employment. They may also find that some of that parental organizing ability will be needed to create a church community that responds with love to their children with disabilities.

If you are searching for a faith community that will welcome you and your child, here are several strategies to consider:

• *Be specific when you ask for a service for your child.* Requesting "membership" is too vague. Decide on the services your child needs, then come up with a plan. If your child is of preschool age, consider preschool or nursery-school classes at your church or synagogue. If your child is older, ask for age-appropriate religious education that is integrated with the other children. If your child wants to be part of a youth group, watch for an opportunity to sign up for a specific activity in which the child has had some experience.

• *Ask the right person for the service you need, and ask for it at the right time.* Although the priest, minister or rabbi is the key to a faith community, a request for special services may confuse him or her and lead to a response that is less than you expected. If you are seeking religious education, ask the education coordinator during a quiet moment. Better yet, call for an appointment and take your child with you. It's hard to refuse when the child is sitting there. And the opportunity to meet the child in person may reduce fears and misconceptions.

• *Check with nearby members of the same faith to see if other congregations are offering the services your child needs.* You may decide to move your membership to a church or synagogue that provides these services, or you may be able to meet with the personnel involved in a model program to get some strategies for taking the first steps in your own faith community.

• *Don't give up if the response is not immediate.* Ask again, and the second time bring along some resources that will help church or synagogue personnel learn about similar services provided elsewhere.

• *Call some of the national faith group resource offices listed in the directory beginning on page 38.* Many serve as information clearinghouses or distribute resources and other curricula and other materials to serve local congregations.

THE SPECIAL OLYMPICS CHRISTMAS ALBUMS

The Pointer Sisters Eurythmics Whitney Houston
Bruce Springsteen and the E Street Band The Pretenders John Cougar Mellencamp
Sting RUN D M C. U2 Madonna Bob Seger & the Silver Bullet Band
Bryan Adams Bon Jovi Alison Moyet Stevie Nicks

AM

Jimmy Mulzet

A dream of meeting the pope comes true

On a clear summer night more than a year ago in Denver, Colorado, "Jimmy" Mulzet's dream of meeting Pope John Paul II came true. Mulzet not only spoke during a Mass celebrated by the pope at World Youth Day, but he was also hugged and blessed by the pontiff.

"The day I met the pope in Denver I really wanted to ask him, 'Why did God make me handicapped?'" Mulzet says. "I wanted to talk to him. But the Mass had to go on."

Mulzet, 37, grew up on the Upper East Side of New York City. The son of the late Frank and Hazel, he was educated in special education programs within the New York City public schools. Mulzet, who was diagnosed with cerebral palsy and developmental delays when he was three years old, is a mailroom messenger at the City University of New York.

"I am one of God's special children," Mulzet says. "He wants me to go out and help people because God helps those that help themselves."

Cardinal John O'Connor has asked Mulzet to read during Masses, including Midnight Mass on Christmas Eve at St. Patrick's Cathedral. "I write to him and tell him what I'm doing," Mulzet says of their friendship. "He is a very good man."

After speaking at World Youth Day in 1993 in Denver, Colorado, Mulzet was hugged and blessed by Pope John Paul II.

When Cardinal Terence Cooke of New York died, Archbishop John O'Connor came to take his place. At the time, I was working at City University, where there was a welcoming party for O'Connor. I didn't know O'Connor or Monsignor John McCarthy, O'Connor's right-hand man. They came to the party in a big black limousine. That was the first time I met my friend—John O'Connor.

I had my picture taken shaking hands with my new friend. There were a lot of people there that day, but I was the only one that got his blessing. Only me—but then no one else asked him!

When the cardinal left I helped him put on his coat and I walked with him outside and talked to him about Cardinal Cooke. I was happy he was here, but I was sorry that Cardinal Cooke died. I opened the door and helped him into the limousine. Ever since that day, me and Cardinal O'Connor have been good friends.

The first Mass

In October of 1989, Cardinal O'Connor told one of the sisters at Catholic Charities he wanted someone to read at the special Mass for the handicapped. She asked me to do it. One of the sisters at Catholic Charities practiced with me. I could not read it right away. One sister said, "You've got to read this right because the cardinal said he wants you to." I went home and practiced.

I was not scared on the day of the Mass. I waited for my time and I read it and it was beautiful.

Midnight Mass

A few days later, a sister from Catholic Charities called, "Jimmy, the cardinal wants you to read again at Midnight Mass for Christmas at St. Patrick's Cathedral." I practiced and practiced. I was not a good reader at the time. I did not learn reading very well at school.

The night came. My hands were sweaty. The cardinal was there. As soon as I saw him, I knew everything was alright. I was so happy.

When it was my turn, I wasn't nervous. I took my time. I started to read and did it without stopping! I know I made the cardinal happy. After Mass, we all went to his residence and had a little party.

continued on page 36

907

"I'd like to meet the pope"

Two or three weeks later, I went right up to the cardinal and said, "Your Eminence, can you do something for me?" I told him I'd like to meet the pope and tell him about my disability. He said, "We will see."

I know the cardinal and Monsignor McCarthy tried to find a way to send me to Rome. But there was no one to take me. I called Monsignor McCarthy every week to ask about the pope.

Then one day we found out the pope was going to Denver for World Youth Day (WYD) in August 1993.

I asked Cardinal O'Connor if I could go. A few days later I got the call; I was going.

Most of the people I was going with told me, "We're just going to WYD. We're not going to meet the pope. If you want to meet him, you'll have to talk to Cardinal O'Connor or make some other arrangements."

A participant in the Special Olympics, Mulzet often speaks on behalf of the games.

Meeting the pope

I got a call from the WYD office. Cardinal O'Connor recommended that I speak in Denver at the candlelight vigil with the pope. I was so excited. My face lighted up.

That is when everyone started contacting me. I was in the *New York Post* and on the radio and television. Everyone wanted to interview me. It made me feel very special.

On Friday morning, I was taken to Cherokee State Park where we rehearsed for the candlelight vigil.

The next day—the biggest day of my life—was Saturday, Aug. 14. There were a lot of people at the candlelight vigil; more than 200,000. I was on the stage with the priests, cardinals and bishops. I saw three helicopters coming. The pope was in one. They landed in a field. And then the pope's car pulled up to the stage's back entrance. The crowd was yelling like he was a king.

I was the fourth person who was going to talk about their faith in God. We were told we only had two minutes.

When it was my turn, I walked out and I saw the pope sitting there. I spoke for exactly seven and a half minutes. I had to say how much I loved God. Then I turned and bowed to the pope. He picked up his hand and told me to come to him.

There were three steps up to his seat. Someone helped me up the stairs. When I got there, the pope gave me such a big hug. The biggest hug that you ever saw!

A few people got to touch the pope, but he did not give them a big hug. When I gave him a hug, I patted him on

SCHOLARSHIPS AVAILABLE

Up to five college scholarships are being offered for the fall of 1995 for a four-year period. Each scholarship provides $3,000 per year ($12,000 total) to each student. Only current high school seniors and college freshmen will be considered.

Applicants should be physically challenged, in a wheelchair, and could not attend college without this help.

All young men and women will be considered without regard to race, color, creed, or state of residence. A private interview is **not** required.

We require a 500-word "statement of need" explaining your physical condition, educational background, and financial status. For scholarship application, write to:

"Doc" and Alicia Keim, Chairscholars
Silver Dollar Ranch, No. 38
Odessa, FL 33556
(813) 920-2737

Deadline Jan. 15, 1995

Chairscholars

"Helping physically challenged students in chairs go to college."

Circle # 267

908

the back and that is when he handed me rosary beads and a cross. That is when I wanted to stand up there and tell him about my disability. But I could not chit-chat with him. Maybe I can one day in Rome.

The Pope said, "God loves you." That made me very special and very blessed.

"In the peace of Christ"

When Cardinal O'Connor went over to Rome after that, he brought back a letter and a picture of me and the pope hugging. It was signed, "In the peace of Christ."

I have realized why God made me the way I am. He wants me to go out and share the Gospel. It is like God gave me a special gift that no one else has. I am one of God's special children.

My soul feels very peaceful now, lots more than it did before this wonderful experience ever happened to me. My body is calmer. I don't get excited like I did before. I just let things come to me with the love of Christ. I know whatever God wants me to do he will tell me in his own special way. Now I want to tell everybody, "Whatever you want to do in life, do not give up. Pray to God and God will help you because He loves you."

The original version of this article—"Jimmy Mulzet's Lifelong Dream Comes True: As told to his friend, Sister Bernadette Downes, CIJ"—first appeared in NCPD National Update, the newsletter of the National Catholic Office for Persons with Disabilities.

- Remote hand control calls the Handi-Move to your bedside.
- Patented gripping system assures a safe, secure fit.
- Shoulder strength not needed.
- Leaves your seat unobstructed.
- Choice of overhead track or free-standing movable unit.
- Streamlined design permits lifting even where the ceiling is low.
- Rugged construction and 2-year warranty.

handi-move PATENTED
982 Route 1–Pine Island, NY 10969
(800) 724-5305

Circle # 35

One size does not fit all!

Children's Specialized Hospital is dedicated exclusively to serving the special needs of children and adolescents.

- Child Study Team
- Learning Disabilities
- Attention Deficit Disorder
- Early Intervention / Pre-School
- Speech and Hearing
- Psychological Services
- Rehab Technology
- Occupational Therapy
- Physical Therapy
- Cognitive Remediation
- Day Hospital
- Recreational Therapy
- Augmentative Communication/ Computer Evaluation
- Nutritional Counseling

Children's Specialized Hospital

MOUNTAINSIDE • FANWOOD • TOMS RIVER
For information in North Jersey call **(908) 233-3720** Ext. **8429** or **8439**
For information in Central and South Jersey call **(908) 914-1100** Ext. **706**

Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation" – the highest distinction awarded by the Joint Commission on Accreditation of Healthcare Organizations.

Circle # 185

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free
1-800-777-1111
24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 86

FAITH GROUP RESOURCES

This directory has been adapted from one in *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and their Families, a Bibliography and Address Listing of Resources for Clergy, Laypersons, Families and Service Providers, 1994 Edition.* This vast 60-page bibliography was compiled and published by the Religion Division of the American Association on Mental Retardation (AAMR) in cooperation with The University Affiliated Program of New Jersey/UMDNJ, Building Community Supports Project. The complete bibliography may be purchased for $10 from AAMR Religion Division, 31 Alexander Street, Princeton, NJ 08540.

Using this directory

For ease of use, resources are listed by denomination and/or faith group. Interfaith/Interdenominational resources are listed at the end. However, please note that many denomination-specific organizations also serve as interdenominational or interfaith resources; those in this category are identified by an asterisk (*) following the group's name. Therefore, individual readers may find useful resources throughout the list.

The numbers following each organization's listing correspond to services listed in the key and provided by that group.

Updates to come

The compilers of the bibliography have not yet identified resources for children and adults with disabilities in some faith groups. *Exceptional Parent* is eager to hear from any national faith group resources that have been omitted from this directory; as additional information becomes available, the directory will be updated.

American Baptist Churches, USA
National Ministries Resources*
PO Box 851
Valley Forge, PA 19482-0851
(610) 768-2464
(610) 768-2470 (FAX)
2,5,6,7,8

Christian Church (Disciples of Christ)
National Benevolent Association
11780 Borman Dr, Ste 135
St Louis, MO 63146-4157
(314) 993-9000
(314) 993-9018 (FAX)
3,4,5,8

Christian Reformed Church
Committee on Disability Concerns*
2850 Kalamazoo Ave SE
Grand Rapids, MI 49560
(616) 246-0837
(616) 246-0834
1,2,3,4,5,6,7,8

Church of the Brethren
Association of Brethren Caregivers*
1451 Dundee Ave
Elgin, IL 60120
(800) 323-8039
(708) 742-5100, ext 275 (TTY)
(708) 742-6103 (FAX)
2,4,5,7,8

Church of Christ
Christian Church Foundation for the Handicapped*
PO Box 9869
Knoxville, TN 37940
(615) 579-0883
(615) 579-0942 (FAX)
1,2,3,4,5,6,7,8

Church of Jesus Christ of Latter-day Saints (Mormons)
The Church of Jesus Christ of Latter-day Saints Special Curriculum*
Church Office Bldg
50 E North Temple, 24th Fl
Salt Lake City, UT 84150
(801) 240-2477 (Voice/TTY)
(801) 240-1727 (FAX)
1,2,4,5,7,8

Church of the Nazarene
Children's Ministries*
6401 The Paseo
Kansas City, MO 64131
(816) 333-7000
(816) 333-4439 (FAX)
1,2,3,4,5,6,7,8

The Episcopal Church
Diocesan Office on Ministry with Persons with Handicaps
c/o St James Episcopal Church
3225 E Minnehaha Pkwy
Minneapolis, MN 55417
(612) 729-5322
2,3,5,8

Evangelical Covenant Church in America
Covenant Resource Center
3200 W Foster Ave
Chicago, IL 60625
(800) 338-4332
(312) 478-2622 (FAX)
5,6,8

Evangelical Lutheran Church
Disability Ministries
Division for Church in Society
8765 W Higgins Rd
Chicago, IL 60631
(800) 638-3522, ext 2692
(800) 442-3522 (TTY)
(312) 380-2707 (FAX)
2,3,5,8

Martin Luther Home Society, Resource Center*
Mill Towne Bldg
650 J St, Ste 305
Lincoln, NE 68508
(800) 443-4899
(402) 434-3250
(402) 434-3253 (FAX)
1,2,3,4,5,6,7,8

JAF Ministries*
PO Box 3333
Agoura Hills, CA 91301
(818) 707-5664
(818) 707-2391 (FAX)
1,2,3,5,7,8

Jewish
Association of Jewish Special Educators
Special Education Center
Board of Jewish Education
426 W 58th St
New York, NY 10019
(212) 245-8200
(212) 247-1957 (FAX)
1,2,3,4,5,8

Council for Jews with Special Needs*
32 W Coolidge, Ste 102
Phoenix, AZ 85013
(602) 277-4243 (Voice/TTY)
(602) 266-7875 (FAX)
1,2,3,4,5,6,7,8

National Jewish Council for the Disabled
YACHAD for the Developmentally Disabled
Our Way for the Jewish Deaf
c/o Orthodox Union
333 7th Ave
New York, NY 10001
(212) 563-4000, ext 229 (YACHAD)
(212) 563-4000, ext 234 (Our Way)
(212) 564-9058 (FAX)
YACHAD: 1,2,3,4,5,9 (developmental delays)
Our Way: 3,4,5,9 (deaf)

KEY

1. Specialized curricula for religious education
2. Disability awareness materials
3. Newsletter or other periodical
4. Consultations to local non-religious organizations
5. Consultations to local congregations
6. Referrals to other resources
7. Serves people from other faiths/denominations
8. Serves all disability groups
9. Serves specific disabilities only

Union of American Hebrew Congregations (Reform)
Liheyot Advisory Committee
Department of Education
838 5th Avenue
New York, NY 10021
(212) 249-0100
(212) 249-2407 (FAX)
1,2,3,5,6,8

United Synagogue of Conservative Judaism
155 5th Ave
New York, NY 10010
(212) 533-7800, ext 2300
(212) 353-9439 (FAX)
2,5,6,8

Mennonite Churches in USA & Canada
Mennonite Mutual Aid*
Advocacy and Educational Resources Department
1110 N Main Street
Goshen, IN 46526
(800) 348-7468
(219) 533-5264 (FAX)
2,3,5,7,8

Moravian Church in America
c/o Linda Marsh*
2718 Winslow Lane
Winston-Salem, NC 27103
(910) 768-8923
2,6

The Presbyterian Church, USA
National Ministries Division, Health, Education, and Welfare Association
100 Witherspoon St
Louisville, KY 40202-1396
(502) 569-5800
(502) 569-8034 (FAX)
2,3,5,8

910

Reformed Church in America
Office for Education and Faith Development
4500 60th St SE
Grand Rapids, MI 49512
(616) 698-7071
(616) 698-6606 (FAX)
5,8

The Roman Catholic Church
Center for Ministry with Disabled People*
University of Dayton
Dayton, OH 45469-0317
(513) 229-4325
(513) 229-4000 (FAX)
2,4,5,7,8

National Apostolate with People with Mental Retardation
4516 30th St NW
Washington, DC 20008
(800) 736-1280
(202) 686-6716 (FAX)
1,2,3,4,5,6,9 (mental retardation)

National Catholic Office for Persons with Disabilities
PO Box 29113
Washington, DC 20017
(202) 529-2933 (Voice/TTY)
(202) 529-4678 (FAX)
1,2,3,5,6,8

Southern Baptist Convention
Baptist Sunday School Board*
127 Ninth Ave N
Nashville, TN 37234
(615) 251-2673
(615) 251-3866 (FAX)
1,2,4,5,7,8

United Church of Canada
c/o Sharon Sanderson*
91-3520 Downpatrick Rd
Ottawa, ON K1V 8T4
Canada
3,4,5,6,7,8

United Church of Christ
United Church Board for Homeland Ministries*
700 Prospect Ave
Cleveland, Ohio 44115-1100
(216) 736-3272
(216) 736-3803 (FAX)
1,2,5,6,7,8

United Methodist Church
The General Board of Global Ministries*
Health and Welfare Ministries Program Department
475 Riverside Dr, Rm 350
New York, NY 10115
(212) 870-3870
(212) 749-2641 (FAX)
(212) 870-3709 (TTY)
1,2,3,4,5,6,7,8

Interdenominational and Interfaith Resources
American Association on Mental Retardation/Religion Division*
31 Alexander Rd
Princeton, NJ 08540
(908) 235-4447
2,3,7,8

Bethesda Lutheran Homes and Services*
National Christian Resource Center
700 Hoffman Dr
Watertown, WI 53094
(800) 369-4636
1,2,3,5,6,7,8

Christian Council for Persons with Disabilities*
7120 W Dove Ct
Milwaukee, WI 53223
(414) 357-6672 (Voice/FAX)
1,2,3,5,6,7,8

Healing Community*
521 Harrison Ave
Claremont, CA 91711
(909) 621-6808
(909) 399-5532 (FAX)
1,2,4,5,7,8

National Council of Churches of Christ in the USA*
Education for Christian Life and Mission
475 Riverside Dr
New York, NY 10115
(212) 870-2227
2,3,6,7,8

National Organization on Disability*
Religion and Disability Program
910 Sixteenth St NW, Ste 600
Washington, DC 20006
(202) 293-5960
(202) 293-5968 (TTY)
(202) 293-5968 (FAX)
2,5,6,7,8

CHRISTOPHER BOUSLOG

Christopher is nearly three years old now—he walks, talks and loves to play! He has an infectious laugh and hugs everyone he meets. Christopher also has Down syndrome.

When an amniocentesis revealed that Christopher would be born with Down syndrome, his father left his mother, Teri, to await Christopher's birth alone. Fortunately, Teri was a member of a church with an active Disabilities Ministry. Because this was a difficult pregnancy, Teri was put on bedrest early. The church's Disabilities Ministry secured a place in the church preschool for Christopher's older brother, and took him to and from school every day. Volunteers cleaned Teri's house, prepared meals and did the laundry.

Teri and Christopher Bouslog greet their "fans" after playing the roles of Mary and the baby Jesus in a Christmas musical production at Crossroads Christian Church in Corona, California.

During these first years of Christopher's life, the volunteers and staff of the Disabilities Ministry have provided Teri with free, quality respite care and supported Christopher's successful inclusion in Sunday school. They have also supplied funds for Teri and her boys to attend retreats designed specifically for families that have a member with a disability and helped church members understand the challenges of raising a child with a disability.

Christopher has become the darling of the preschool set, and has won the hearts of the whole congregation. Most importantly, Christopher is an accepted and *appreciated* member of his large church family, and has taught pastors and peers alike the meanings of perseverance, patience and unconditional love.

—Jane L. Simmons

National Council of Churches of Christ Committee on Disabilities

Recognizing that persons with disabilities bring unique gifts to the life and ministry of the church, the National Council of Churches of Christ (NCCC), Committee on Disabilities seeks wholeness in the church by promoting full inclusion and participation of all persons.

The NCCC Committee on Disabilities is a consortium of representatives appointed by their denominations to serve as a "think tank" in the area of disabilities.

The committee also engages the expertise of consultants who voluntarily assist its work in the areas of inclusive education, bio-medical ethics, seminary/pastoral education, family issues, legislative issues and research and evaluation.

The collective work of the committee encourages denominational commitment. It broadens the information base through sharing and evaluating resources, program models, research studies, denominational policies and policies. The committee enables denominations to participate in joint projects such as leadership conferences, media development and consultations.

For more information contact: National Council of Churches, Ministries in Christian Education, 475 Riverside Dr., Room 848, New York, NY 10115, (212) 870-2287.

RAISA PUHACZ

My eight-year-old daughter, Raisa, has tuberous sclerosis. She has seizures. She cannot walk or communicate. She needs someone to take care of all her personal needs. Despite these obstacles, I've always wanted Raisa to participate in the same activities as her peers.

My husband, Ihor, and I are members of St. Josephat's Ukrainian Catholic Church in Bethlehem, Pennsylvania. Three years ago, an announcement in the church bulletin encouraged all parish families to enroll their children in religious education classes.

I wanted Raisa to be a part of those classes. I wanted her to make her First Communion—just like her cousins. But I wasn't sure what our pastor, Father Daniel Gurovich, would think. I called him to ask if Raisa could be included.

Students (left to right) Nestor Hrycenko, Andrew Behler and Raisa Puhacz join their religion teacher, Mary Rybak, for opening prayers in religion class at St. Josephat's Ukrainian Catholic Church.

"I just assumed you'd enroll Raisa," he said quite simply. "And if you didn't, I was going to call and insist she attend."

Then I began to worry about the children in Raisa's class. Would they like her? Had they ever been around a child with a disability?

I prepared a speech to introduce Raisa to the other children. As the first day of class approached, I became more and more nervous. As executive director of The Arc of Lehigh and Northampton Counties, I give speeches all the time. But this one was making me more nervous than I'd ever been.

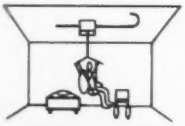
When I began speaking, a youngster raised his hand and said, "I know all about disabled kids; I go to school with them." I didn't need to say another word—Raisa was a part of the class.

When I picked Raisa up after that first class, her teacher said, "Remember that boy who said he knows all about kids with disabilities? At closing prayer, Andy said, 'Thank you, God, for giving Raisa such a nice smile.'"

When I reached the car, tears filled my eyes. I cried all the way home.

Last May, Raisa made her First Communion with her classmates. She wasn't given any special recognition. She was treated like a typical kid—all we'd ever wanted.

— Stephanie Hnatiw



Barrier Free Lifts

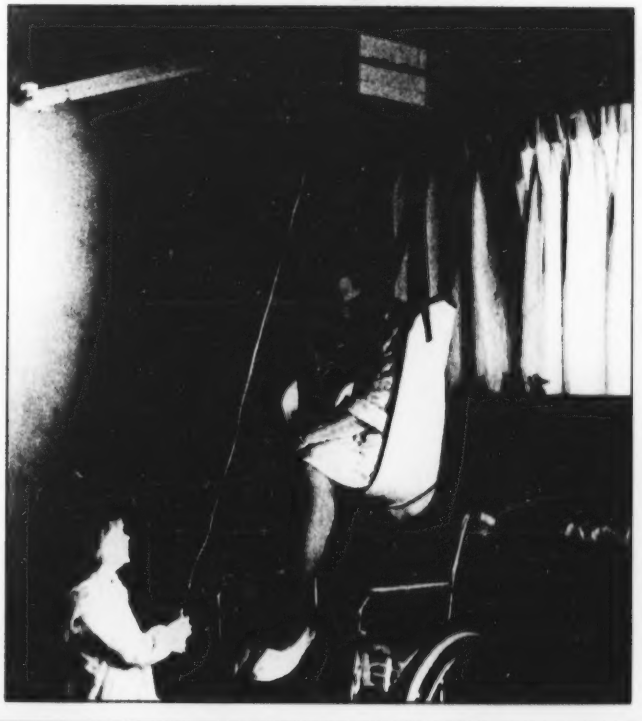
BARRIER FREE CEILING LIFTS ARE

- **Used independently!**
  Most physically challenged people can transfer themselves unassisted.
- **Air tube controlled!**
  No electricity to the user!
  No chance of being shocked!
  Can operate while in water!
- **Multi-directional!**
  Vertical & horizontal motion at the push of a button.
- **Battery operated & no maintenance!**
  Batteries are automatically recharged each time the lift is used.

Helping You Achieve Greater Mobility

Barrier Free Lifts, Inc.

P.O. Box 4163 • Manassas, VA 22110
(703) 361-6531 • FAX (703) 361-7861
1-800-582-8732



Circle # 217

912

For the Love of Peter

"While trying to nurture his gifts, I discovered my own."

by Ginny Thornburgh

Let me tell you about our son Peter. He is 34 years old and just over six feet tall. He has dark hair and thoughtful eyes. My husband, Dick, and I agree that Peter is the most handsome of our four grown sons. He is an avid baseball fan and roots for both the Pirates and the Phillies. He lives with a roommate in an apartment in Harrisburg, Pennsylvania, and attends church regularly.

Maybe what I appreciate most about Peter is his quiet, uncluttered faith. Three years ago on Christmas Eve when my mother, Dick, Peter and I were seated around the dinner table, I decided it would be a good idea if we each took a turn and talked about what Christmas meant to us.

"Peter, what is important about Christmas?" I asked. There was a long silence. Finally Peter spoke.

"Jesus," he said. That was all.

What's so surprising about any of this? Nothing, really, except that Peter has severe mental retardation.

[Above] Peter Thornburgh, age four. [Right] The Thornburgh brothers (from left) John, Peter, Bill and David enjoy a 1992 Christmas gathering at John's home in Pittsburgh, Pennsylvania.

When Peter was four months old, he was in a car accident. His mother—Dick's first wife—was killed. His two older brothers, John and David, sustained minor injuries, but Peter suffered extensive brain damage.

When I married Dick in 1963, Peter was almost four years old, still wearing diapers. He did not speak or walk. Beneath his scalp, a large section of his skull had been removed to prevent additional pressure on the brain. He was on medication for seizures and was susceptible to infections. He required constant care, but I was a young, energetic former schoolteacher, full of optimism.

We lived in Pittsburgh at the time, and we enrolled him in a private preschool for children with special needs, where the teachers gave us useful techniques for working with him. When he woke in the morning and after naps, Peter was a great babbler. So we put a tape recorder beside his crib. Then, the school's speech pathologist used these sounds as building blocks to develop Peter's speech.

One morning when it was still dark, Dick woke me up. "Listen!" he said.

Peter was calling his first word, "M-ah-ah-m." *Mom.*

What about Peter?

Peter was six and a half when our fourth son, Bill, was born. Until then, we had always had a babysitter at home for Peter when we went to church. Now with Bill home too, members of the congregation began to ask, "When are we going to see that beautiful new baby of yours in the nursery?" *What about Peter?* I thought. *Why don't they ask about Peter?*

I was hurt and angry. Peter had a right to come to church too. "We need to welcome everyone, including children with mental retardation," I told the congregation.

We created space in the church for a classroom. We found a woman with a special education background, who volunteered to teach. We put a notice in the church bulletin and placed an ad in the local paper. Finally the first Sunday came up. Only one child showed up—Peter.

I cried and cried. I felt humiliated. What was all our hard work for? Did other parents of children with mental retardation feel so alone? Were they so accustomed to being excluded that they couldn't even imagine a welcoming church?

With Dick's encouragement, I recruited children from Peter's preschool for our church school. We also became involved with our county chapter of the Association for Retarded Citizens. At one meeting, I was surprised when an older mother said ominously, "Be prepared. The day will come when you'll have to fight for your son."

Pot holders

That day came when, at age eight, Peter was ready to enter the public school system. I made an appointment to visit our district elementary school and learn about their program for children with disabilities. On a dark rainy

913

day, I checked in at the office of the old brick building and asked where I might find Peter's class.

"In the basement," came the reply.

I went down a flight of stairs and through a maze of hallways to the building's furnace room. Barely concealed by a makeshift wooden screen, the furnace spewed soot into the dank, musty air. The only daylight came from four small windows near the ceiling. Seepage from rain ran down the walls. Seated at two tables was a group of children, aged six to 12, making pot holders. Pot holders!

By the time I returned upstairs to meet with the school principal, I was trembling with rage. "This can't... This

Each child was unique in God's sight. They couldn't be ignored. I wouldn't let it happen.

doesn't seem to be a very good place for children," I stammered. "The furnace, the dampness, the lack of sunlight, the pot holders..."

"Oh," he replied coolly, "they don't care."

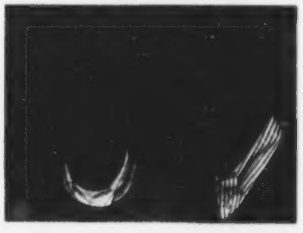
They do care! I wanted to shout. *And I care. They're people just like you and me.* Each child was unique in God's sight. They couldn't be ignored. I wouldn't let it happen.

Becoming an advocate

Joining forces with other volunteers, I set out to see what conditions were like in our state's institutions. To our dismay, the conditions we found were wretched.

At one of the state's oldest institutions, we discovered residents deemed unmanageable being kept in cages. One adolescent boy was cramped in a metal box so small he couldn't stretch his legs. The investigation that followed our visit in 1973 resulted in the firing of the institution's superintendent, the banning of cages and state funding for upgrading facilities and retraining staff.

At another facility, residents were dying from accidents and injuries at an alarming rate. The day before our visit, a young man who required a diet of pureed food had choked to death on a chunk of meat. We headed straight for the school's kitchen and seized a sample tray, including a portion of gristly meat, which we later presented to members of the state legislature at an emergency meeting.



Some called us troublemakers, but gradually Pennsylvania established itself as a leader in institutional reform and placement of people with mental retardation.

One day I was called as a witness for a hearing about a state-licensed facility I had visited. As the interrogating senator kept interrupting me, demanding yes or no answers, I became flustered. I felt my cheeks become hot and tears fill my eyes. The worst moment came when the senator in charge leaned into the microphone and said patronizingly, "There, there, Mrs. Thornburgh. We don't want to upset you. You may be excused."

Outside I vowed, *This work is too important. I will never cry in public again.* And with God's help, I haven't.

In 1979, Dick was elected to the first of two terms as governor of Pennsylvania. That's when I began to grasp that the advocacy work I'd done was little more than a drop in the bucket. Every day I responded to letters requesting help, not only for people with mental retardation but with other disabilities as well.

When Dick's appointment as attorney general took us to Washington, I continued my advocacy work as director of the Religion and Disability program of the National Organization on Disability. Although people with disabilities face architectural and communication barriers, I soon learned that the most insurmountable barrier is prejudice.

"You have to remember, Ginny," Dick would remind me at the end of a long day, "not everyone has a Peter Thornburgh in her life."

Peter changed my life

The culmination of my work, and the tireless advocacy of countless others, came on July 26, 1990. On that brilliant summer day, in an outdoor ceremony on the South Lawn of the White House, President George Bush signed the Americans with Disabilities Act into law.

Standing in the warm sun, holding Dick's hand, I thought of Peter. While still severely limited, he had become much more independent—riding city buses, going to church, sharing pizza and laughter with friends in his supervised apartment. He had come so far. But then I was struck with the most amazing thought—*So have I.*

Because of Peter, I learned how to fight for what I believe. I learned how to speak out and stand up to injustice. While trying to nurture his gifts, I discovered my own gifts for communication and organization. Peter changed my life. And for that I'll be forever grateful.

Ginny Thornburgh is the director of the Religion and Disability Program at the National Organization on Disability (NOD) in Washington, DC. A graduate of Harvard University's Graduate School of Education and Wheaton College in Norton, MA, Ginny is the editor of LOVING JUSTICE: THE ADA AND THE RELIGIOUS COMMUNITY *and* THAT ALL MAY WORSHIP. *She has received many awards and nine honorary degrees for her years of community service.*

Thornburgh's husband, Dick is counsel to the Pittsburgh-based law firm of Kirkpatrick & Lockhart in its Washington, DC office. With a public career spanning 25 years, he has served as governor of Pennsylvania, attorney general of the United States and undersecretary-general of the United Nations. The Thornburghs have four sons and five grandchildren.

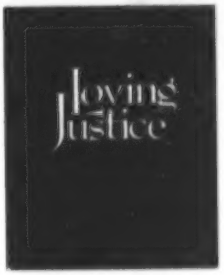
This article has been reprinted with permission from GUIDEPOSTS MAGAZINE. *©1993 by Guideposts Associates, Inc., Carmel, New York 10512.*

914

A Comprehensive Look at Disability Laws and the Religious Community

LOVING JUSTICE: THE ADA AND THE RELIGIOUS COMMUNITY, *edited by Ginny Thornburgh, is a companion volume to* **THAT ALL MAY WORSHIP** *(see sidebar below). Both $10 books are available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.*

Reviewed by Robert C. Anderson



The much-anticipated companion volume to *That All May Worship* is now available—and worth the wait! *Loving Justice: The ADA and the Religious Community* builds upon the foundation of its predecessor with particular emphasis on the ADA (Americans with Disabilities Act of 1990) and other relevant disability laws as they relate to the religious community.

This work is a collaborative product of disability leaders and lawyers from Christian and Jewish traditions. The groups are concerned with increasing the religious participation of persons with disabilities. In addition, the core information will be published under the same name, *Loving Justice*, through denominational offices of the Roman Catholic, United Methodist, Evangelical Lutheran and Episcopal faiths.

Highly readable in content and presentation, the guide benefits from informed but down-to-earth input from noted authorities in the fields of religion, disability and the law.

"Are religious organizations subject to the ADA?" Jim Brady, vice chairman of the National Organization on Disability, writes on the inside cover. Contrary to popular belief, the answer is a surprising "Yes! And to a higher authority as well."

In 36 concise pages, *Loving Justice* informs the reader of portions of the ADA which do indeed apply to religious institutions. Chapter One offers an easily digested summary of the act's key provisions, along with frequently asked questions. The second chapter describes the relationship between the ADA and other legislation. In a narrative question-and-answer format, Chapter Three addresses specific requirements of the law pertaining to the religious community. A comprehensive list of resources and glossary of key terms are included at the end of the guide.

Key concepts, ideas and implications

Because our government honors the separation of church and state, places of worship and other religious institutions have historically received exemption from governmental control while remaining subject to the bounds of the law itself. This delicate tension preserves our religious liberties while protecting the rights of the individual from the freedoms of other citizens. This relationship is not breached by the ADA, although its provisions must be noted by religiously-related entities.

For example, religious institutions may be subject to the employment provisions of ADA if they operate residential housing, daycare, health care or formal educational programs which provide services to the community. There are also a number of other instances where ADA provisions apply. Congregations and religiously-affiliated groups which provide facilities for school groups, blood drives or health clinics may have compliance factors to consider. Religious groups which operate senior citizen meal programs or homeless shelters may also have compliance concerns if they operate under the scope of a municipal program or receive federal, state or local subsidies.

Similarly, religiously-affiliated colleges or

THAT ALL MAY WORSHIP

That All May Worship is a 52-page handbook that describes three kinds of barriers people with disabilities face in becoming involved with religion and gives ideas about how to knock them down.

• **Architecture.** Ramps, curb cuts and handrails are a welcoming sign to people with disabilities. For people who use wheelchairs, crutches, or walkers, many congregations offer seating with extra leg room or "pew cut." Some choir areas are being renovated to accommodate people in wheelchairs.

• **Communication.** Improved sound systems and brighter lighting can help those with visual or hearing impairments. Hymnals, prayer books, programs and Bibles in large print or Braille help too. Some congregations provide listening devices or have sign language interpreters.

• **Attitude.** How can you make a person with a disability feel welcomed? "I think of Peter, who has been given specific responsibilities at his church," says Ginny Thornburgh. "He fills the pastor's water glass and helps with the Sunday school children. After the service, he straightens the hymnals and collects stray bulletins. He goes to church every Sunday knowing he is needed. Each of us deserves as much."

915

Hey Mom, Now There's A Break From the Weather

The WEATHERBREAKER™
A COLLAPSIBLE CANOPY FOR WHEELCHAIRS/SCOOTERS

- Protects your child from the rain
- Shades your child from the sun
- Fits all wheelchairs
- Mount it once, then put it on or take it off in a snap

Call your local dealer today!
or order direct
800-795-2392

The WEATHERBREAKER™ *Base Model $115.00*

When Ordering Include:
1. Manufacturer and model of Wheel Chair/Scooter
2. Choice of teal green, navy blue, cranberry red or charcoal gray
3. Side windows add $20.00, Rear window add $10.00

Checks – Money Orders – Credit Cards Accepted
DIESTCO Manufacturing • P.O. Box 6504 • Chico, CA 95927
Quality Guaranteed • Made in the USA

Circle # 252

An important journal that brings together religion and disability and rehabilitation!

Journal of Religion in Disability & Rehabilitation

NEW!

innovations in ministry for independent living

Co-Editors: William A. Blair, DMin
Chairperson, Board of the State of Alabama Independent Living Council
Dana Davidson Blair, RN, MA
Writer and Lifestyle Adjustment Consultant, Options Consultants

"It is about time that a resource such as this is available. The journal has articles which WILL LEAD ONE TO GREATER UNDERSTANDING AND CARE WITH, OF, AND FOR PERSONS WITH DISABILITIES. . . . The journal will not have a place on my shelves but will be on my desk and reading table."
–Rev. David O. Kyllo, MDiv, Director of Chaplaincy, Rehabilitation Institute of Chicago

The journal keeps religious professionals up to date about developments in the field of disability and rehabilitation in order to help them enhance the lives of those with disabilities and those who care for them.

Call for Papers: Potential authors are encourage to request an "Instructions for Authors" brochure from either William Blair or Dana Davidson, Journal of Religion in Disability & Rehabilitation, 6473 Pine Tree Lane, Pinson, Alabama 35216; Tel: (205) 681-1457.

Volume 2, No. 1–Spring 1995. Quarterly (4 issues).
Volume 3, No. 1–Spring 1996. Quarterly (4 issues).
Subscription rates (per volume):
Special Discounted Rate for Individuals: $34/ Institutions: $48/ Libraries: $60

The Haworth Pastoral Press
An imprint of The Haworth Press, Inc.
10 Alice Street, Binghamton, NY 13904-1580 USA
TEL: 1-800-342-9678 • FAX: 1-607-722-6362

EAD94

other educational entities are generally exempt unless students receive federal grants or guaranteed loans. In other instances, the responsibility for providing accessible accommodations and services rests with the state or political jurisdiction. For example, congregations which occasionally serve as polling sites for elections are not specifically responsible for compliance regulations; rather, the state or local government must ensure that the polling sites they select are accessible.

One issue frequently raised by congregations is that they don't have any persons with disabilities who come to their facility. That may be true simply because they cannot get inside, or do not feel welcomed when they enter. As with the general public, 17 percent of congregational members have one or more significant disabilities.

Congregations which voluntarily comply with ADA requirements are simply doing the right thing.

Theological and Moral Imperatives

The heart of the matter is not whether a religious institution can be exempted from legal compliance; the constitution, by and large, resolves this issue. For congregations to embody the mission of hope and love which they so fervently treasure, the real challenge is to be proactive, becoming as inclusive as possible. "Reasonable accommodation" is a spirit of fairness and equity already built into the ADA. As stated in the introduction to *Loving Justice*, "If supermarkets and bars are more accessible than altars, then we must all bear the shame."

Religious institutions do not seek to exclude or make persons with disabilities feel unwelcome, although this message is conveyed—in very subtle terms—more frequently than congregations would like to admit. The religious community prides itself as the sacred bastion of God's love, where all are accepted as equals in personhood and access to the Divine. And yet many persons have no access to religious facilities. How can they honestly conclude that these places of worship (and hence God) really care about them? This double standard may be covertly at work within the faith community.

The message of this guidebook is clear: justice and love will triumph only when segregating walls are knocked down and when the barriers of architecture, communication and attitudes are removed. Only then will people with disabilities become full participants in the celebrations and obligations of their faith.

This seminal work is a must-have for those committed to becoming more creative, caring communities of faith.

Robert C. Anderson, M.Div., is the director of Pastoral Care Services at Lakeshore Rehabilitation Hospital, ReLife Rehabilitation Systems, in Birmingham, Alabama.

This review of LOVING JUSTICE *will appear in the* JOURNAL OF RELIGION AND DISABILITY AND REHABILITATION, *Vol. 2, Issue 1 (Haworth Press), edited by Dr. William A. and Dana D. Blair. For information about the journal contact the Blairs, 6473 Pine Tree Lane, Pinson, AL 35126, (205) 681-1457.*

916

Buying and Converting

What you need to know about van lifts and ramps

Janet Vohs never thought about learning to drive while she was raising her daughter, Jessica. Because Jessica uses a wheelchair, Vohs knew any automobile she owned would have to be a customized van with a lift to transfer Jessica and her wheelchair in and out of the van.

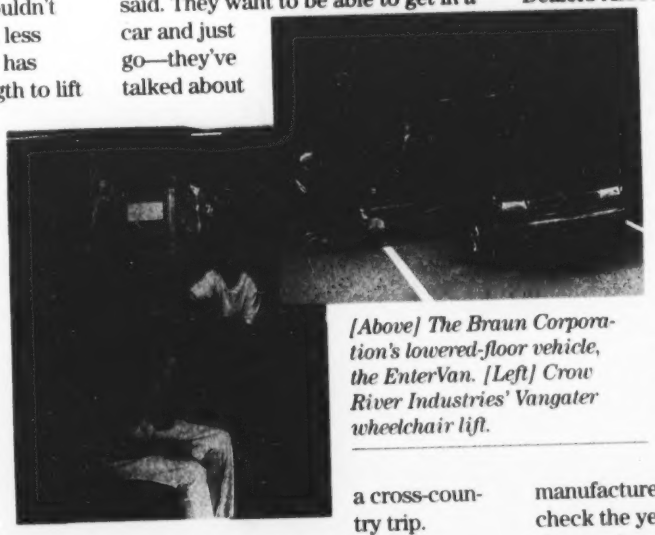
"Being a single parent, I couldn't afford it," Vohs says. As for a less expensive car, Vohs says she has never had the physical strength to lift her daughter in and out of a car.

When traveling from their Boston-area home, Vohs and her daughter would take buses, taxi cabs and accessible vehicles provided by the Massachusetts Bay Transit Authority.

However, it has not always been that simple. For example, this summer the two couldn't get a ride to the Massachusetts State House—10 minutes away by car—where Jessica was to testify at a hearing on community living for people with disabilities. Instead, the two had to make a 90-minute trip by foot and wheelchair.

Limited travel options can leave people like Jessica isolated. Between the ages of 14 and 21, Jessica attended a residential school program. But when she came home, it was hard for her to visit her best friend who lived an hour away by car.

Now, Jessica is 23 and living on her own with a live-in aide. Jessica and her aide are adventurous types, Vohs said. They want to be able to get in a car and just go—they've talked about a cross-country trip.



[Above] The Braun Corporation's lowered-floor vehicle, the EnterVan. [Left] Crow River Industries' Vangater wheelchair lift.

Vohs wants to buy them a van because the aide's car is not in great shape and is too small for Jessica's power wheelchair.

"We're going to have to get something secondhand," Vohs says. "I still don't know how we're going to pay for it. And we want a van so we can get the wheelchair in it."

Vohs is just one of an increasing number of people inquiring about accessible vans and equipment, says Rebecca Plank, executive director of the National Mobility Equipment Dealers Association (NMEDA), a 195-member trade group of accessible automobile and equipment dealers.

"A lot of people are finding out the equipment is out there and is available to them and they want to have their independence too," Plank says.

Finding a dealer

- About 400 equipment dealers nationwide sell and install products from any of the more than 20 equipment manufacturers. To find a local dealer, check the yellow pages under "Van Conversion & Accessories."
- Find a reputable dealer. Ask to see documented proof that the dealer has been trained by the manufacturer to install its equipment. State rehabilitation offices, the Veteran's Administration and NMEDA (800/833-0427, voice) may help you find a dealer.

Once you are happy with a particular dealer, continue to do business there. With an ongoing relationship, it will be easier and more comfortable for you to define your needs and goals in the future.

What kind of van and equipment?

- Many mini- and full-size vans allow wheelchair users to sit in the driver and front passenger areas.
- Full-size vans may fit more than one wheelchair user.

Renting an Accessible Van

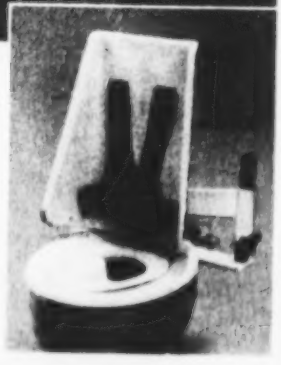
Many families rent an accessible van when traveling, when they do not own one or when they need one while theirs is being repaired.

- You can find a rental company which has accessible vans through a travel agent or in the yellow pages under "Truck Renting & Leasing."
- The cost of the van rental will depend on where you rent it, what kind you rent and how long you rent it for.
- Ask where the van has to be picked up and dropped off. Many rental companies will deliver the van to you and pick it up when you are done.
- If using a rental van on vacation, many rental companies will provide you with information on accessible hotels and vacation attractions. They may also provide you with information on packing wheelchairs and other necessities when traveling to a destination by plane.

917

The choice is easy . . .

A Columbia Toilet Support gives your child independence, privacy and secure support



The choice is easy – when you have a choice! That's why we offer 5 models to suit *your* child's support needs.

- Easy mount, easy off!
- Adjustable height
- Fits any toilet: school, home or institutional

Ask for our FREE Full Color Catalog of Convenient, Helpful Products

It includes the unique Columbia Car Seat, now crash-tested for children **20 to 102 lbs.**, up to 5 feet tall!

Handsome, durable and convenient to use!

Contact us for your nearest dealer

COLUMBIA

Circle # 11

• If converting a van, the adaptive equipment, and in some cases, the medical equipment you need, should fit comfortably and securely in the vehicle. Also, make sure the van's roof is high enough for the wheelchair's sitting height, which is the distance between the ground and the wheelchair user's head while seated in the wheelchair. The wheelchair user should also be able to look out the window.

• Certain vans and/or equipment may not work as well as others under different weather conditions. Some may have problems in extremely cold or hot temperatures. Manageability in severe weather conditions is another factor to consider.

Ramps and lifts

• Decide whether you want a lift or a ramp. If you do not have the strength to constantly lift your child, a fully- or semi-automatic lift may be the way to go. Fully-automatic lifts usually allow the transfer of a wheelchair user without the help of someone else because they lift and lower electronically. Semi-automatic lifts require you to do part of the job, such as unfolding and refolding a part of the lift. Many lifts come with manual back-up systems in case there are problems that prevent electronic operation.

• A ramp can be used on all vans. Some ramps can be bolted to the floor inside the side or rear door. When not in use, the ramp folds up and is stored just inside the door. Portable ramps—ones which are not permanently attached to the van—can be repositioned to meet different needs. However, portable ramps usually are not as strong and stable as bolted ones.

Price

• Health insurance companies generally do not cover the purchase of accessible vans and/or equipment, usually claiming they are "luxury" items. Medicare and Medicaid also do not cover the costs.

• Many van manufacturers offer rebates ranging from about $750 to $1,500 when converting one of their vans.

• Many equipment installers may not cut the frame of a van to accommodate specific equipment because this could void a manufacturer's warranty.

It is hard to say how much it will cost to buy an accessible van or convert one. "Everybody's disability is as different as their fingerprint," Plank says. "Their transportation needs are that different, too." *—Marc S. Malkin*

Thanks to the following experts and companies for their contributions to this article: ABLEDATA; Rebecca Plank, executive director of the National Mobility Equipment Dealers Association; Andrew Goodyear, owner of the Wheelchair Getaways franchise in southern Florida; Jeff Hermanson, first vice president of The Braun Corporation; KneelKar Mednet, Inc.; Crow River Industries; Independent Mobility Systems, Inc.; Ricon Corporation; Bruno Independent Living Aids; the Ford Mobility Motoring Program; the Physically Challenged Assistance Program of the Chrysler Corporation; the General Motors Mobility Program; Care Concepts; Vantage Vans and Wheeler's Van Rentals.

NEW PRODUCTS

CHAMELEON

This three-in-one stander for infants allows parents and therapists to create numerous positions, and changes from a stander to a stroller or high-chair. All positions keep the child cradled against cushioned supports. Other features include a removable tray and a folding lightweight frame. The unit's colorful upholstery is removable and washable. All materials are non-toxic.

J.A. Preston, Jackson, MI 49204

Circle # 141

BEEPERKID

You can keep an eye on your child while giving him or her the freedom of moving about with BeeperKid. This child-monitoring system is an unobtrusive device for keeping children within a safe distance, especially in crowded areas. The system consists of two clip-on units. The parent's unit beeps and its light flashes when the child moves further than 15 feet away. It works from behind closed doors and around corners.

A+H International Products, Inc., Long Beach, CA 90802

Circle # 142

BASIC SIGN LANGUAGE FOR CHILDREN

Specifically designed for children with developmental delays, this Signed English video series uses a split screen to simultaneously show a picture of an object, action or word and an individual demonstrating the sign. Each sign is presented twice with time in between for practice. Three 30-minute videos presenting different vocabulary groups are available.

See-Sign Productions, Naples, FL 33963

Circle # 143

THE REMINDER

If your child requires medication or treatment during the school day, this product could help the school staff to remember to administer it to him or her—and up to 63 other students who require medication. This treatment management system is designed to enable a school policy of centralized medication control in a self-contained unit. Audible alarms and visual messages for each scheduled treatment are provided. The unit also prints out a record of the day's treatment activities.

Fishburne International, Inc., Arden, NC 28704

Circle # 144

YOUR BABY HAS DOWN SYNDROME

Produced as a tribute to Mackenzie Sara Noca, a girl with Down syndrome who died at three months of age, this video is an emotional and educational journey about parenting a child with Down syndrome. Factual information and advice is provided by William Cohen, M.D., director of the Down Syndrome Center in Pittsburgh.

Mackenzie Sara Noca Charitable Trust, Pittsburgh, PA 15239

Circle # 145

THE STOCKTON BED

This height-adjustable, age-appropriate bed is available in a rainbow of colorful finishes to fit the decor of any child's bedroom. It has crib-type safety sides and a high-low mechanism for both caregiver convenience and child safety. The Stockton Bed comes in five-, six- and seven-foot lengths. Electric push-button models are also available.

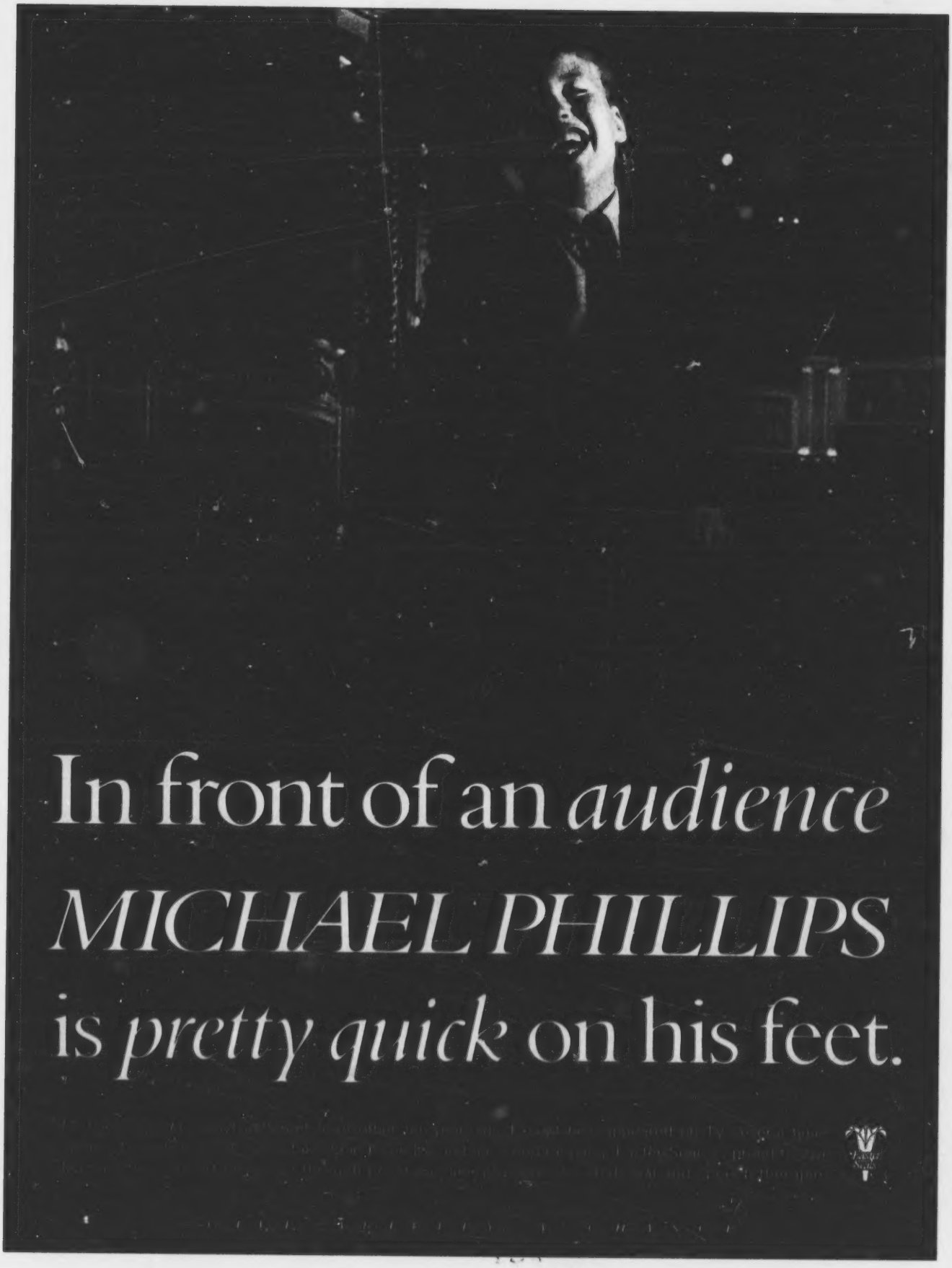
HARD Manufacturing, Buffalo, NY 14215

Circle # 146

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT*'s "Free Product & Information Card." Readers can circle a number on this issue's card (page 59) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TTY, (301) 588-9284, V/TTY or (301) 587-1967, FAX.

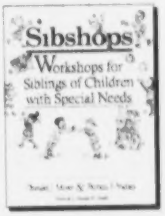
919


In front of an *audience*
MICHAEL PHILLIPS
is *pretty quick* on his feet.

Information Needs of Siblings

by Donald J. Meyer

This article is an excerpt from SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS *(Paul H. Brookes, 1994). This is the final of four excerpts* EXCEPTIONAL PARENT *will publish.* SIBSHOPS *is available through* EXCEPTIONAL PARENT LIBRARY, *(800) 535-1910.*



Throughout their lives, brothers and sisters will have a need for information about their siblings' special needs... Siblings need information for reassurance, to answer their own questions and questions posed by others and to plan for their future. And, unless their brother or sister has a terminal condition, informational needs will be lifelong.

Throughout their lives, the types of information siblings need—as well as how it is optimally presented—will vary with the siblings' age...

Preschoolers

Preschoolers need to know that they cannot catch their siblings' disability, nor did they cause the condition. These concepts—while obvious to adults—may not be clear to a young child who has caught her sister's cold and has a preschooler's sense of causality.

Explanations of disabilities or illnesses to children at this age should be as clear as possible... One way to explain a disability is to describe it in terms of differences in behavior or routine. A four-year-old who accompanies his two-year-old sister to an early intervention program may understand his sister's disability this way: "Down syndrome means you have to go to school to learn how to talk..." While clearly incomplete, a definition like this can be the foundation for more involved explanations at later ages.

School-aged children

During their grade-school years, siblings need information to answer their own questions about the disability or illness as well as questions posed by classmates, friends or even strangers...

More so than preschoolers, school-age children may have more specific questions. They may ask: "Why can some people with cerebral palsy walk and some can't?" "What does amniocentesis mean?" "What's physical therapy? Does it hurt?"...

Teenagers

Because they can envision a life beyond their parents, teenagers and young adults require additional information about their siblings' future and what role they will play in that future. If parents have not made plans by this time, it is critical that they begin and encourage brothers and sisters to be a part of this planning...

Avoiding misconceptions

Some parents, seeking to protect their children from the sadness they are experiencing, choose to tell their children as little as possible. But when left in the dark about what is happening to a brother or sister, siblings may make up their own stories that are worse than the truth. They may even blame themselves for their siblings' conditions. Obtaining information, then, can be reassuring, even comforting...

With rare exceptions, most books and materials about disabilities and illnesses have been created for adults... Siblings are also frequently excluded from another traditional source of information—teachers, physicians, therapists, nurses and other service providers... Relegated to waiting rooms, siblings report feeling ignored or isolated...

ILLUSTRATION BY CARY PHILLO LASSEN

Some siblings are reluctant to ask questions, having witnessed their parents' sadness about the disability or illness. When a child does not ask questions, parents may assume he or she has no interest in the topic. Sisters and brothers tell us that parents must be proactive in offering information...

If children's questions about siblings' special needs are answered in a forthright manner, and if they are made to feel glad that they asked, they will not only gain a growing understanding of their siblings' special needs but will also become confident that they may approach their parents whenever they have questions...

Into the loop

Inviting—but not requiring—siblings to attend meetings with service providers can benefit all parties. When included, siblings can obtain helpful, reassuring information about a sibling's condition, and can contribute by providing information, and unique, informed (and frequently unsentimental) perspectives on issues such as barriers to inclusion with neighborhood age peers, or a sibling's ability to accomplish household and self-care responsibilities...

When invited to meet with service providers, siblings are brought "into the loop." A message is sent to family members and service providers alike that brothers and sisters are valued members of the child's "team." Including them acknowledges the important roles they play in their siblings' lives and, for many, roles they will have as adults...

Donald J. Meyer is the director of the Sibling Support Project at Children's Hospital and Medical Center in Seattle, Washington.

921

ASK THE DOCTOR

by David Hirsch, M.D.

Transition to Oral Feedings; Felbamate

Q My four-year-old son has a syndrome called Cornelia de Lange. As a result of this condition, he was born with low birth weight and anomalies (defects occurring during fetal development) of his arms and hands. He has a small jaw. He is also moderately mentally retarded.

He has had significant feeding difficulties from the beginning. In spite of considerable effort by my husband and myself, we had to place a gastrostomy "button" at about six months of age. However, over the last three years we have continued efforts to feed him orally. Now, he is able to take some of his feedings orally but he shows significant defensiveness and aversion when oral feedings are attempted; he tries to avoid the food by turning his head and refusing to open his mouth. I am afraid he might aspirate (breath in) some of his food because he is fighting instead of swallowing. Do you have any suggestions on how we should proceed? What else should we watch for?

A First of all, congratulations on getting as far as you have. It certainly can be very difficult going from enteral (tube feeding) to oral feedings especially after a few years. About 75 percent of children with Cornelia de Lange syndrome, sometimes called Brachmann-de Lange, have significant problems with feeding. They typically have marked retardation of growth which makes adequate nutrition even more important. However, your child's weight should not be a concern unless it is unduly low for his height.

You have taken the right steps in attempting to feed him orally at his *own* pace. Speech and occupational therapists and a dietitian can help you develop a feeding program specifically for your son.

With regard to aspiration, this is more often a problem in infants with Cornelia de Lange than in older children with the syndrome, although precautions need to be taken *anytime* there is a potential risk. Children with this syndrome also have a higher incidence of other gastrointestinal problems such as esophageal dysmotility (the esophagus does not propel food to the stomach properly), gastroesophogeal reflux (the stomach contents come back up the esophagus), hiatal hernia (a small portion of the stomach protrudes through the diaphragm) and esophagitis (irritation of the lining of the esophagus). Before continuing with more aggressive oral feedings, your pediatrician may want to evaluate your son for these or other potential feeding problems by ordering radiographic (x-ray) studies or by consulting with a pediatric gastroenterologist. Appropriate medical intervention for these problems can make the transition from enteral to oral feeding easier on your child and yourself.

Feeding aversion or oral defensiveness are potentially significant problems. A child who has not eaten orally for a long time and has "forgotten" how to eat or who has experienced unpleasant reactions to oral feedings, such as choking or reflux (severe heartburn caused by abnormal backflow of stomach contents), may develop an avoidance reaction or aversion to oral feedings.

Many people believe that children who are tube-fed never have a sense of "hunger." In my experience, this is not true. Their stomachs still empty and they feel "hungry" (unless they are fed continuously or with "drip" feedings). However, the satisfaction of tasting food will not be there with tube-feeding so you will want to encourage this feeling by offering foods that typically taste good and that have a texture your son can handle.

You might want to make sure that everyone feeding your son is aware of his transition to oral feedings and is patient with him, but still able to feed him within a reasonable period of time—usually 30 to 45 minutes and never less than 20 minutes.

Experienced speech pathologists, occupational therapists and dietitians can be very helpful with your son's transition to oral feeding. Again, go at your child's own pace to avoid exacerbating these problems.

More information about your son's condition may be obtained by contacting the Cornelia de Lange Syndrome Foundation, 60 Dyer Ave., Collinsville, CT 06022-1273, (800) 223-8355.

***Ask the Doctor** is a regular department of EXCEPTIONAL PARENT in which questions are answered by David Hirsch, M.D., a pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch mentions specific products or medications, he is illustrating his suggestions; he is not endorsing any specific products.

*To submit a question, write or fax: **Ask the Doctor**, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

BEST COPY AVAILABLE

Q My eight-year-old daughter has a form of epilepsy called Lennox-Gastaut. It is a complicated type of epilepsy for which we have tried many types of anticonvulsants (medications to control epilepsy) without very good results. About 10 months ago, my daughter's neurologist put her on a new medication called Felbamate. Her seizures have significantly decreased and, more importantly, her quality of life has improved. Recently, however, her neurologist advised me that some potentially serious side effects of the drug have been reported. He recommended that she be weaned off the medication. Is there anything else that can be done?

A This is really an unfortunate situation. Felbamate, sold under the brand name Felbatol, seemed to be a medication that was effective in reducing seizures, especially in children with Lennox-Gastaut and other types of complex or difficult-to-control seizure disorders. In spite of extensive evaluations and clinical trials which showed Felbamate to be safe and effective, and approval by the Federal Drug Administration (FDA), an unexpected but marked increase in the occurrence of aplastic anemia (a very severe blood disorder) and/or liver failure has been associated with the use of the medication. The FDA has decided to continue to make Felbamate available because of its effectiveness for certain conditions, especially Lennox-Gastaut.

Listen to the advice of your daughter's neurologist. Never stop a medication without consulting the physician who has prescribed it. He or she, in conjunction with your own observations and feelings about what is best for your daughter, will help you make the best decision.

TheBOSS

INDEPENDENCE MOBILITY

Photo used with permission from Hoveround Corp., Bedford, PA

SWITCH OPTIONS

PROPORTIONAL CONTROL

REMOTE CONTROL

Five Models Available

1-800-950-5185

INNOVATIVE PRODUCTS, INC.

Grand Forks, ND 58201

Circle # 42

Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms

Innovative learning center with unique, year-round curriculum

Hydrotherapy in an indoor therapy pool and hubbard tank

Augmentative communication systems developed along with total communication

Intensive physical therapy

Around-the-clock advanced medical care

Associations with leading specialists and major medical centers

Affiliation with SUNY

Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

923 Circle # 6

Pen Pals

Children & Teens

Scott Richards: Age 9, male. Has brother with Coffin-Lowrey syndrome; likes rock-collecting and karate. Wants to hear from anyone.
RR #1, Box 1889E, Whitefield, ME 04353

Marsha Lynn Yarmus: Age 18, female. Has cerebral palsy; enjoys board games and loves hockey, especially the New York Rangers. Wants to hear from males aged 19–23 with cerebral palsy in the New Jersey area.
124 Somers Ave., Bergenfield, NJ 07621

Ian Perge: Age 18, male. Has cerebral palsy. Participates in the New York State Games for the Physically Challenged, competing in track and field, swimming and wheelchair basketball. Likes music, plays bass in a band. Wants to hear from young adults (ages 17–20) with or without disabilities.
24 Townsend Pl., Syosset, NY 11791

Noa Elimelech: Age 7, female. Has a four-year-old brother with developmental delays. She is in the second grade. Wants a pen pal who understands her situation.
18356-B Collins St., Tarzana, CA 91356-2406

Adults

Betsy Edwards: Has 16-year-old son with mental retardation and autistic tendencies and an adult brother with mental retardation and mild cerebral palsy. Collects postcards. Wants to hear from anyone, especially divorced parents of children with special needs.
107 Cloverbloom, Victoria, TX 77904

Catherine Haynes: Has a five-year-old son with cerebral palsy and severe mental retardation who walks with help, rolls over and sits up. He is non-verbal. Wants to hear from parents around her age (22) who have a child like hers.
516 Rasco Road West, #1, Southaven, MS 38671

Justin and Laurie Laurenzi: Parents of 20-month-old boy, who has congenital myopathy and hypotonia. He is fed through a g-tube, has a trach and is on a ventilator while sleeping. He is very bright and can sit up, but cannot walk or crawl. Want to correspond with families with similar children. Hope to start a local support group.
238 A Fairmount Ave., Blackwood, NJ 08012

Darlene French: Mother of two teenagers; one who is microcephalic with severe mental retardation, the other with learning disabilities and diabetes. Enjoys sewing, reading, crafts and animals. Wants to hear from "those who enjoy the challenge of life's experiences."
HC 63 Box 17, Dornsife, PA 17823

Send Pen Pal requests to: Pen Pals, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. All requests should include a daytime phone number (to reach you, not for publication), three sentences introducing yourself and the type of pen pal you want. Children's requests must also include their age and sex and a parent's signature indicating permission to publish the child's request.

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Medicaid and HMOs

Q Because of his disability, my son has been covered by Medicaid since shortly after birth. He has seizures, microcephaly, cortical blindness, low muscle tone, brain damage and a possible metabolic disorder.

We have always had him on our private insurance in addition to the Medicaid coverage. Until recently, we have had a traditional 80/20 insurance plan with a deductible. While we were on this plan, all claims were first sent to our private insurance company. Any remaining balance was paid by Medicaid. We had no expense for Medicaid-authorized procedures or services. Our only cost was the private insurance premium.

Due to the cost of that premium, we recently switched to an HMO that covers 100 percent of most expenses once the co-pay is met. Like before, we still pay our son's HMO premium. But now, in addition, we have started receiving bills for past-due co-payments for my son's medical treatments. The "co-pays" add up rather quickly because of my son's frequent hospitalizations and doctor visits.

We carry our son on our private health insurance policy because we feel it is our financial responsibility to pay the insurance premium we would pay if he did not have a disability. It seems that Medicaid should prefer that we pay the private insurance premium for our son, leaving them responsible only for the co-pay amounts. In fact, they should be happy we are now part of an HMO that pays a higher percentage of his medical bills. Instead, Medicaid seems to be penalizing us. Apparently, they don't look at it from a financial standpoint. In my conversations with Medicaid personnel, they seem to be encouraging us to drop our son from our private insurance policy.

Should we take this drastic step? If so, he would be left with only Medicaid, and they would be responsible for all of his medical bills. Would dropping him from our private insurance policy cause us problems with Medicaid? I don't want to make a mistake and end up being responsible for all of my son's medical bills if Medicaid decides not to pay.

A.L., Nebraska

A In theory, when a child is covered both by Medicaid and private insurance, Medicaid will act as secondary insurer. This means Medicaid considers paying any co-pay amounts remaining after the primary insurer has paid its portion of the bill.

However, although Medicaid is a federal program, many of its very specific rules are set at the state level. Medicaid programs in many states work successfully with both traditional insurance and managed-care programs, including HMOs. In those states, switching from a traditional insur-

924

ance program to a managed care program as primary insurer would probably not lead to any difficulties.

But in some states—including Nebraska—the situation is somewhat different. According to a Nebraska Medicaid representative, when a traditional insurance program is a primary insurer for a Medicaid recipient, that insurer usually itemizes the claim, listing the amount it has paid and the amount remaining as co-payment. Nebraska Medicaid rules allow payment of any remaining amount, up to the maximum allowed.

Some managed-care programs, however, require consumers to pay the co-payment amount *prior* to the provision of services. In this situation, the Nebraska Medicaid program does not cover co-payments. This is because, technically speaking, a co-payment made prior to services rendered does not represent an amount remaining after the primary insurer's payment. It seems like a minor difference, but it's significant in terms of the Medicaid rules in Nebraska.

Possible changes

More than 1,000 Medicaid recipients in Nebraska are affected by this situation. That number is likely to grow as managed care becomes more widespread.

Medicaid officials in Nebraska are aware of the problem and are considering a series of rule changes, including a request for a federal Medicaid waiver that would allow for the payment of co-pay amounts even when the primary insurer requires co-payments to be made prior to services. Still, it's likely to be quite a while before any changes go into effect.

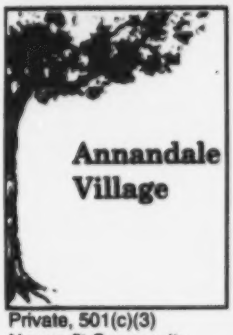
Explore your options

Review options with your attorney, a state Medicaid caseworker or an attorney at the local legal services office so you can make a reasonable decision.

Since Nebraska's Medicaid rules may change, however, the decision you make at this point may provide only a temporary solution. Follow the situation closely, and be prepared to make appropriate changes in the future.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146. Fax questions to (617) 730-8742.*

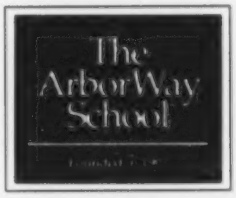
If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To ensure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.



Private, 501(c)(3)
Nonprofit Community

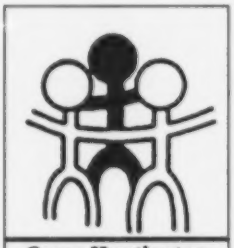
"THEIR COMMUNITY...WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381



THE ARBORWAY SCHOOL
A 24 hour integrated learning experience which provides individualized services for multihandicapped students.
- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710



Camp Huntington
33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

"MAXIMIZING INDIVIDUAL POTENTIAL"
Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

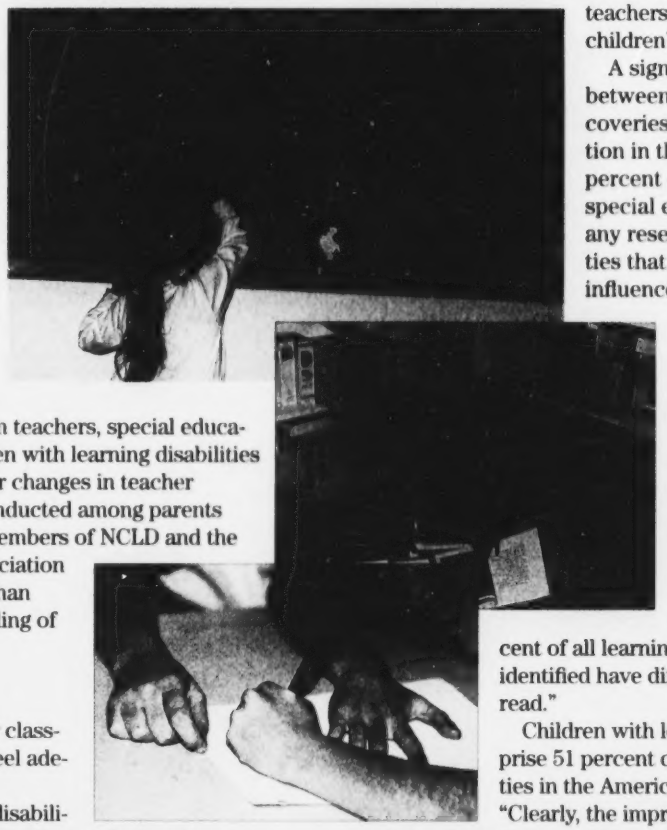
Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

Are They Ready to Teach Our Kids?

A national survey shows a widespread lack of confidence in the readiness of regular classroom teachers to educate children with learning disabilities.

Parents of children with learning disabilities are convinced that regular classroom teachers aren't adequately trained to teach their children—and almost half the teachers agree, according to a recent survey conducted for the National Center for Learning Disabilities (NCLD).

This situation poses a serious threat to the education of the 10 percent of American children with learning disabilities, warns the NCLD, a leading organization for people with learning disabilities.



PHOTOGRAPHS CLAIRE YAFFA

The survey of classroom teachers, special educators and parents of children with learning disabilities suggests a critical need for changes in teacher preparation practices. Conducted among parents and teachers who were members of NCLD and the Learning Disabilities Association of America (LDA), more than 1,500 of the original sampling of 5,000 responded.

The findings

Only 53 percent of regular classroom teachers surveyed feel adequately trained to teach youngsters with learning disabilities compared to 89 percent of special educators.

However, 98 percent of parents of children with learning disabilities are convinced that general educators are not trained to teach children with learning disabilities. Both regular and special educators overwhelmingly expressed a desire to reverse this negative trend, with 80 percent wishing to learn more about special techniques for teaching children with learning disabilities.

Of the 540 teachers who answered the question asking if "inclusion is a very supportable approach to education for all children," 54 percent agreed; 76 percent felt general education teachers are "receptive to the logistical and teaching demands of inclusive classrooms."

Among the educators and parents who did not feel general education teachers are adequately prepared to teach children with learning disabilities in regular classrooms, most agreed that the two top priorities for educating children with learning disabilities should be to "develop and institute a concrete plan for teacher preparation prior to the implementation of an inclusion program and to give teachers the tools to cope with children's diverse needs."

A significant gap exists between promising research discoveries and their implementation in the classroom. Only 50 percent of all teachers, including special educators, were aware of any research on reading disabilities that could positively influence their teaching practices.

"This alarming disparity strongly indicates that teacher training is behind the times," said Dr. Tom Hehir, director of Special Education Programs at the U.S. Department of Education. "This is unfortunate, since approximately 75 percent of all learning disabled children identified have difficulties learning to read."

Children with learning disabilities comprise 51 percent of children with disabilities in the American public school system. "Clearly, the improved ability of our teachers to teach reading would have significant effects on literacy levels overall," said Dr. Reid Lyon of the National Institute of Child Health and Human Development.

These findings were obtained for the National Center for Learning Disabilities (NCLD) by NFO Research, Inc. of Greenwich, Conn. Established in 1977, NCLD is an advocacy group for people with learning disabilities. NCLD provides national and information referrals; educational programs; public awareness and understanding campaigns and legislative advocacy.

This survey was released during Learning Disabilities: A National Responsibility, a two day summit sponsored by NCLD in Washington, DC Sept. 20–21.

For more information on the survey and NCLD, contact NCLD, 381 Park Ave. South, Suite 1420, New York, NY 10016, (212) 545-7510.

926

NEW IMPROVED

To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call... (800) 333-0003.

Circle #165

WHAT'S HAPPENING

Just For Kids

• *HiP* is a new non-profit magazine for 8- to 14-year-olds who are deaf or hard of hearing. Publishers Ellen Dolich and Robin Gladstone, parents of children with profound hearing impairments, plan to publish *HiP* six times a year.

Features include profiles on outstanding people who are deaf and hard of hearing, movie and video reviews written from a deaf perspective, an advice column written by a deaf child and a comic strip starring a superhero who is deaf.

A free sample copy is available upon request; annual subscriptions are $14.95. *HiP*, 1563 Solano Ave., #137, Berkeley, CA 94707, (510) 523-4221.

• Membership in the Halo Club is free to all brothers and sisters of children with ***Angelman syndrome*** (AS). Members receive a newsletter full of cartoons, stories and pictures sent in by each other. Club friends and their parents are planning a 1995 get-together at the Angelman Syndrome Foundation conference in Colorado Springs.

To join the Halo Club, contact Ashleigh Evans, 13280 Caminito Mar Villa, Del Mar, CA 92014, (619) 481-8781.

• Children with visual impairments can now receive the monthly newsletter *Young Environmentalist's Action (YEA)* in Braille. Published monthly by Global Response, an international environmental education group, *YEA* teaches young people about environmental issues and how to protect the earth. Topics include rainforest destruction, endangered species protection, marine mammals and air and water pollution. *YEA* (also available in English and Spanish) is free, but donations are accepted. Contact Global Response, P.O. Box 7490, Boulder, CO 80306-7490, (303) 444-0306.

• The Pen-Pal Program of the Children's Hopes & Dreams Foundation serves children with disabilities and chronic or life-threatening illnesses who are 5–18 years old. Children are matched with pen-pals of the same age and sex. The program has contact with more than 5,000 hospitals, clinics, camps for children with serious illnesses, Ronald McDonald Houses and Dream/Wish groups in more than 25 countries. The service is free; enrollment cards are available from Children's Hopes & Dreams Foundation, 280 Route 46, Dover, NJ 07801, (201) 361-7366.

When Young Children are Injured

When Young Children are Injured. Families as Caregivers in Hospitals and at Home is a new guide for families with infants, toddlers or preschoolers who have sustained serious injuries, including traumatic brain injuries, spinal cord injuries, near drownings, major burns or other injuries that have caused a disability. The guide is intended to let parents know that they are not alone and to give families practical information for decision-making. Topics addressed in the guide include siblings; helping your child with pain and discomfort; finding support for family members; leaving the hospital and letting go once the child is home. $7.50; bulk rates available. Available from Exceptional Parent Library, (800) 535-1910.

Publications

• *FAS: Parent and Child* is a handbook about parenting children with fetal alcohol syndrome. The 32-page book covers sleeping, eating, developmental milestones, speech and learning problems, illnesses, sensory disorders, activity levels, behavioral concerns, friendships, family relationships, adolescent issues and parental needs. Also

At Devereux . . .
a helping hand is just a phone call away
1-800-345-1292

In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

Devereux services include:
- residential treatment centers
- community-based group homes
- day treatment programs
- transitional living
- acute and partial hospitalization
- foster care homes
- family counseling and therapy
- in-home services
- aftercare programs

Devereux
Since 1912

Circle # 19

928

The thrill of victory came three times for 17-year-old Jon Rydberg during the 1994 U.S. Open Wheelchair Tennis Championships held Oct. 8–16 at the Racquet Club in Irvine, Calif. During the first weekend, Rydberg, of Pine City, Minn. captured the Junior Open Singles title and teamed with Ricky Molier, of the Netherlands, to win the Junior Open Doubles championship.

But Rydberg would not stop there. He stayed to play with the "big boys," and reached the semi-finals in the Men's B Singles Division before losing a close match to Tennessee's Rocky LeBlanc. Rydberg later teamed up with LeBlanc to claim the Men's B Doubles title.

Rydberg "epitomizes why adaptive sports and recreation programs are vital to the physical and emotional well being of our nation's younger population who have disabilities," commented Brad Parks, founder and president of the National Foundation of Wheelchair Tennis.

included is a list of books, newsletters and support groups related to FAS. The $7.50 book is available from the Fetal Alcohol Education Program at the Boston University School of Medicine, 7 Kent St., Brookline, MA 02146, (617) 739-1424.

• A Spanish edition of *About Hydrocephalus: A Book for Parents* is now available. It is an exact duplicate of the English version which is considered to be the most up-to-date resource on hydrocephalus for families. Members of the Hydrocephalus Association can receive either English or Spanish versions free; $2 for others. Hydrocephalus Association, 870 Market St., Ste. 955, San Francisco, CA 94102, (415) 776-4713.

Kasey was bounced from school to school, program to program for most of his life. Teachers and family tried in vain to break through his aggressive behavior patterns, and curb his tendency to run away without warning. Still, one day he escaped close supervision and dashed into heavy traffic, bringing cars to a screeching halt inches away from impact.

Nothing improved for Kasey or his family until they contacted Heartspring. Here, caring professionals used an interdisciplinary team approach to gain an understanding of Kasey's needs, then tailored a program to reach him.

Heartspring has a unique approach to helping children with autism. Education teams provide 24-hour-a-day coordinated services, implementing therapies designed around *your child's individual needs and personality.* Specialists in the areas of education, speech, psychology, occupational therapy, physical therapy, and residential care work toward the same goals.

Recently Kasey's mother observed an incredible event: her son walked across the Heartspring campus with his personal teacher, making no effort to run away. "I watched him do other things even *I* couldn't get him to do," said his mother. Today Kasey is a happier person — and his family shares his joy.

When you need help reaching your unreachable child, call Heartspring.

We can make a difference.

HEARTSPRING℠

A lifeskills learning center

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800- 835-1043

Formerly the Institute of Logopedics

1934 – Celebrating 60 Years Of Service – 1994

Circle # 38

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

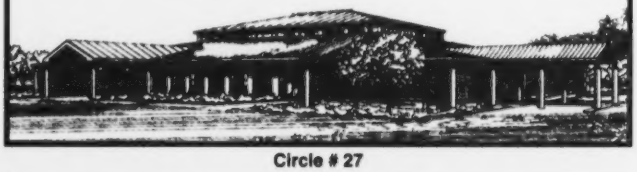
Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597



Circle # 27

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 39

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent!*

Directory of Advertisers

Circle	Advertiser	Page
	Apple Computer	11
217	Barrier Free Lifts	40
6	Berkshire Meadows	51
173	Bethesda Lutheran Home	20
115	Braun	5,7
267	Chairscholars Foundation	36
185	Children's Specialized Hospital	37
13	Columbia Medical	27
11	Columbia Medical	46
14	Crow River Industries	C3
18	Cumberland Hospital	17
19	Devereux Foundation	56
262	Diestco Manufacturing	44
25	Equipment Shop	6
26	Estate Planning	6
27	Evergreen Center	58
35	Handi-Move	37
36	Haverich Ortho Sport	11
	Haworth Press, The	44
38	Heartspring	57
39	HMS School	58
42	Innovative Products	51
7	JA Preston	C4
168	Merrill Lynch	21
169	Milani Foods	55
	National Easter Seal Society	48
171	New England Center for Autism	28
239	Plum Enterprises	3
103	Rhamdec	15
269	Sigma Tau	13,14
	Special Olympics International	34
73	St. Coletta (MA)	20
298	Standard Publishing	C2
194	Toys for Special Children	65
	United Cerebral Palsy	24
86	Woodbury Products	37

Subscriptions

EXCEPTIONAL PARENT
P.O. BOX 3000, DEPT. EP, DENVILLE, NJ 07834
(800) 247-8080 (NEW SUBSCRIPTIONS ONLY)
(800) 562-1973 (CUSTOMER SERVICE)

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $1 per copy, plus $.50 per page is paid directly to CCC, 27 Congress St., Salem, MA 01970. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$1.00 + .50.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106.

Free Product & Service Information

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: December 31, 1994

Expiration Date: March 31, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

Free Product & Service Information

A. Are you a subscriber to Exceptional Parent?

❑ Yes ❑ No (If no, please see the subscription card in this issue.)

Name _____

Occupation/Title _____

Company/Association _____

Address _____

City _____ State _____ Zip _____

Phone(___) _____ Fax(___) _____

B. Annual Household Income (include all family members)

1❑ Less than $30,000 4❑ $50,001 - $75,000

2❑ $30,001 - $40,000 5❑ $75,001 - $100,000

3❑ $40,001 - $50,000 6❑ $100,000+

C. Do you live in a(n):

7❑ Home 8❑ Own 9❑ Rent

10❑ Apartment 11❑ Own 12❑ Rent

D. In all, how many automobiles do you and others in your household own or lease?

13❑ One 14❑ Two 15❑ Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

16❑ one month 18❑ nine months

17❑ three months 19❑ one year

Issue Date: December 31, 1994

Expiration Date: March 31, 1995

Circle #

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200
201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220
221	222	223	224	225	226	227	228	229	230
231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250
251	252	253	254	255	256	257	258	259	260
261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280
281	282	283	284	285	286	287	288	289	290
291	292	293	294	295	296	297	298	299	300

93

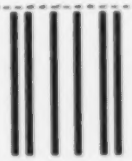
No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFILED MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321



No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321

932

Market Place

Child Care

Working Solutions
51 E. 42nd Street, Ste. 1511
New York, NY 10017
(212) 922-9562
Agency that specializes in placing professional nannies to work with children who have special needs. NY, NJ & CT

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Enabling Devices

ENABLING DEVICES
TOYS FOR SPECIAL CHILDREN
1995 CATALOG
Just Published
A complete guide to capability switches, augmentative communication aids, adapted toys and special devices. **Tel. 1-800-832-8697. Enabling Devices,** 383 Warburton Avenue, Hastings-On-Hudson, NY 10706

Equipment Dealers

National

American Discount Medical
Savings to 25% on Tumbleforms. Equipment and Supplies Discounted to 50%. Call 800-877-9100 for FREE BROCHURE.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

New York

Dowd Medical
1010 Main Street
Buffalo, NY 14202
(716) 883-8188
Dowd has been serving the area since 1930. For personal service and quality equipment call Dowd.

Free Catalogs

Consumer Care Products, Inc.
P.O. Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Summers Laboratories, Inc.
Collegeville, PA 19426
(800) 533-SKIN (7546)
Triple Paste™ for diaper rash and chronic irritation. Used at leading children's hospitals. Available without prescription. Call now for free treatment information.

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Software

UCLA Microcomputer Project
1000 Veteran Avenue/Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
Catalog of dev. appropriate software for children w/disab. 18 mths-5 yrs. Apple, Mac, IBM, cause/effect, game format, basic preschool concepts

Put Your Honey in a Gunny

The *GUNNY SACK™*
Lap, Leg and Feet Cover
- Fleece lined for warmth
- 100% waterproof

To Order Call
800-795-2392
DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

Books for Parents and Professionals

Turtle Books
Approved by the American Academy of Pediatrics. These upbeat stories with warm, colorful illustrations address real issues found in the lives of real children with disabilities. Provide a bridge of understanding for your children with disabilities, siblings & friends. **FREE** Brochure. **Jason and Nordic Publishers,** PO Box 441, Hollidaysburg, PA 16648. FAX (814) 696-4250

Special Angel
An Intro. to Down Syndrome by L.T. & M.P. Nolen. Excellent "first book" with quality photos. Silver edition with 1994 Resource guide. $11.00 "Up with D.S." T-Shirt $14.50. FREE Brochure. **GRAFFITI,** P.O. Box 246, Red River, NM 87558

Catalogs

What It's Like To Be Me, an attractive unique book written & illustrated entirely by children with handicapping conditions. Engaging & candid. A great heartwarming & inspiring gift for all ages. $10.95 + $2.50 (S+H) Check or money order to: **Friendship Press,** Box 37844, Cincinnati, OH 45222

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. **Special Needs Project,** 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Educational Materials

Demystify Spelling!
Related lists for language instruction, vocabulary building, & more. 53,000 vowel-centered words, over 1,000 related categories. Vowel Category Resource Lists - Part One (roots/ inflections); Part Two (roots/ affixes) Both books - **$33.00. Leonardo Press** PO Box 1326EP Camden, ME 04843 (Free Catalog).

FREE—The 1995 Woodbine House/Special-Needs Collection, a catalog of excellent books for parents, children, and professionals on autism, CP, Down syndrome, Tourette syndrome, mental retardation, visual impairment, physical disabilities, special education, and more. **Woodbine House,** 6510 Bells Mill Road, Bethesda, MD 20817, (800) 843-7323.

To place an ad, contact Barbara Nastro at (201) 680-4874

Videotapes

Interax Video
Sign Language Course
Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

1st
Kids Video
Carwash Video
for Special Kids
No talking. Visual voyage thru water-filled action of working carwash. Hours of educational, CLEAN fun! Ages 3+ Color HiFi 25 min. For Home & Schools.
$19.95+s/h 1-800-383-8811

VAN CONVERSION DEALERS

Connecticut

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Illinois

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

VAN CONVERSION DEALERS

(continued)

Kentucky

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Monmouth Vans, Access & Mobility
5105 Route 33/34
Farmingdale, NJ 07727
1-800-221-0034
Car & van modifications/driver or transport. Major Manufacturers: Braun, Crow River, Mobile Tech, & Ricon Lifts; Raise top/lower floor —Sales—Service—Rentals— NMEDA-Quality Assurance Program Member. Plus:—BUILDING ACCESSIBILITY Power Access Door Openers, Stair Lifts, Elevators & Vertical Lifts

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Ohio

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road, Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tennessee

C & C Ford - Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Texas

Lift Aids Inc.
2381 Pecan Ct.
Ft. Worth, TX 76117
(817) 834-3881
Metro (817) 429-7141
Mobility specialist for physically disabled. Largest wheelchair lift installer in Ft. Worth mid cities area. Authorized dealer/installer for Ricon, Crow River, Mobil Tech, Handicaps, Braun, Vantage Mini Vans. 5 star dealer/member of NMDA. Full repair & Service since 1968.

To place an ad, contact Barbara Nastro at (201) 680-4874

National Parent Network on Disabilities Conference Videos and Materials Available

Because many parents cannot take the time or afford to attend the annual meeting, NPND—for the first time ever—is offering highlights of the annual meeting and congressional briefing on video.

NPND members receive a 10 percent discount on all materials:

____ ***1994 NPND Annual Meeting Highlights*** includes presentations by Rep. Major Owens, D-NY, chairperson of the House Select Subcommittee on Education and Civil Rights; Carol Rasco, assistant to Pres. Clinton for domestic policy; leading disability rights advocate Justin Dart and Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services. ($19.95)

____ ***The 1994 NPND Congressional Briefing: The Reauthorization of IDEA: Parents' Perspectives*** includes all of the parent panels. It also contains information parents must understand to protect the access of children and youth with disabilities to a free, appropriate, public education. ($19.95)

____ ***Inclusion: A Parent's View*** is a compilation of parents from around the country sharing experiences regarding the inclusion of their children in neighborhood schools and communities. These vignettes will inform and inspire. ($19.95)

____ ***NPND Legislative Briefing Book*** is a 200-page manual that includes material on the legislative process, legislative issues in education and health care reform, unfunded mandates, effective advocacy for people with disabilities and many other topics. The binder can also be used by NPND members to organize Action Alerts, faxes sent to members alerting them that phone calls or letters to Congress are needed. ($35)

Inclusion Material Available: All of the material developed to support the activities of NPND's inclusion project, All Children Belong (ACB), is now available:

____ ***ACB Train-the-Trainer Manual*** is a 160-page manual containing information helpful for working toward inclusion at any level. It describes ACB's four phases of inclusion and includes useful forms such as the Community Assessment Tool and the Positive Student Profile. Also includes sample training outlines and references for further reading. ($25)

____ ***ACB Related Readings Manual*** is a 325-page collection of readings that provide a comprehensive understanding of inclusion. ($40)

____ ***ACB First National Teleconference*** is a video copy of the nearly three-hour March 1994 teleconference about inclusion. Also includes talks with Tom Hehir, director of the Office of Special Education Programs in the U.S. Department of Education; Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services; Martha Fields, executive director of the National Association of the State Directors of Special Education and parents. ($28)

____ **TOTAL** (NPND members may deduct 10%)

NAME: _____

ORGANIZATION: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

HOME NUMBER (____) _____

WORK NUMBER (____) _____

Please return this form with your check made payable to: NPND, 1600 Prince St., Suite 115, Alexandria, VA 22314, (703) 684-6763, FAX: (703) 836-1232

934

Networking

Information from The National Parent Network on Disabilities

NPND's Annual Meeting is Unparalleled Success

NPND's annual meeting for 1994 was held Oct. 1–3 in Washington, DC. Following a full-day meeting of the board of directors Sept. 30, the annual meeting included panel discussions, talk about legislation and updates on the Americans with Disabilities Act (ADA) and the reauthorization of the Individuals with Disabilities Education Act (IDEA).

Before the annual meeting officially opened, the NPND board of directors attended a working dinner of the Joseph P. Kennedy Jr. Foundation. Eunice Kennedy Shriver, Foundation Executive Director Steve Eidleman and several other foundation staff members attended the dinner. Shriver, who asked NPND board members their opinions on a wide range of topics concerning children with disabilities and their families, stressed the need for parents and other family members to become more politically active. Shriver also suggested that a meeting between the NPND board and the foundation become a regular part of NPND's annual meetings.

National leaders open meeting

Rep. Major Owens, D-NY, chairperson of the House Select Subcommittee on Education and Civil Rights, opened the annual meeting Saturday, Oct. 1. Based on the accomplishments of the House-Senate conference that had completed its work just the day before, Owens spoke about the Families of Children with Disabilities Support Act of 1994 and the reauthorization of the Improving America's Schools Act of 1994, commonly referred to by its previous name, the Elementary and Secondary Education Act.

Arguing that government must reprioritize its spending, Owens advised parents and advocates not to accept many legislators' arguments that money is insufficient to adequately fund disability-related programs. Parents must continue to lead the fight for the rights of students with disabilities, Owens said.

[From left to right] NPND executive director Patricia McGill Smith chats with Eunice Kennedy Shriver and Diana Cuthbertson, outgoing president of NPND's board of directors, at a Joseph P. Kennedy Jr. Foundation dinner Sept. 30.

Rep. Major Owens, D-NY, opens NPND's annual meeting.

Following Owens, Carol Rasco, assistant to the president for domestic policy, shared her experiences of raising a son with disabilities. She said her son had a special friendship with Pres. Clinton and emphasized Clinton's commitment to people with disabilities. Rasco was given the NPND National Leadership Award after her comments.

Leading disability rights activist Justin Dart was also honored Saturday with the NPND Citizen Advocate Award. In an emotional speech, Dart described the upcoming winter as the "Valley Forge" of the disability movement while urging for more advocacy, determination and hope.

Update from the Hill

Other Saturday talks included remarks about the just-ending congressional session and predictions for upcoming legislative actions. Speakers included George Jessien, a Kennedy Policy Fellow working with the Senate Subcommittee on Disability Policy; Hans Meeder, staff to the House Select Subcommittee on Education and Civil Rights; Paul Marchand, director of the ARC Office of Government Affairs and Lucy Watkins, parent advocate for the Center on Law in Education.

Saturday afternoon concluded with a talk by Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services (OSERS). Heumann urged parents to become heavily involved in the reauthorization of IDEA and, in particular, to respond to the questions that her office had put forward in the *Federal Register*.

Bob Williams, commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services, also talked about Heumann's office on Sunday, Oct. 2, saying he was trying to work more closely with OSERS, the Department of Labor and other agencies. Following his presentation, Williams spent time with some parents to discuss

their concerns about the SSI benefits program.

IDEA reauthorization

On Saturday afternoon, meeting participants reviewed, edited and developed policy positions regarding the reauthorization of IDEA. Called *The Reauthorization of IDEA: Parents' Perspectives*, the position paper includes eight principles critical to a new IDEA that will be more responsive to the needs of students with disabilities and their families. This paper is available free to parents and organizations by contacting NPND.

Tom Hehir, director of the Office of Special Education Programs in the U.S. Department of Education, also addressed IDEA on Sunday in a lengthy discussion with meeting participants about various IDEA reauthorization issues the education department is particularly interested in.

NPND awards

NPND held its annual reception and award ceremony Saturday night:

- **Doreen "Pam" Steneberg** received the Parent Leader/Advocate of the Year Award for her work on behalf of children with disabilities and their families in northern California and across the nation.
- **Charles Lazarus**, founder of Toys "R" Us, was named Corporate Leader of the Year for the production of his stores' *Toy Guide for Differently-Abled Children*.

NPND extends special recognition to American Airlines and the National Association of Medical Equipment Services for their generous support of the reception. Other conference and reception contributors included Hal's Pals, Virginia Leingang, Neil's Outrageous Liquors and Deli, Robert Blair Ruble, Sir Speedy, St. James Residence Hotel, Total Audio Visual Systems and the Joseph P. Kennedy Jr. Foundation.

Pam Steneberg [left] received the Parent Leader/Advocate of the Year Award during NPND's annual meeting Oct. 1–3. Diana Cuthbertson, outgoing president of NPND's board of directors, presented the award at a ceremony Oct. 1.

Board elections

An election of NPND board members was held during the business meeting on Sunday. New board members are Marta Anchondo, Margaret Burley and Diana Autin. Jo Butts, Sue Pratt and Pam Steneberg were re-elected.

New board officers were also elected at the first meeting of the new NPND board Sunday evening. Elected were President Jo Butts, Vice President Pam Steneberg, Secretary Janet Vohs and Treasurer Joan Kilburn.

Thanks goes out to former board members Rich Burden, Sweet Alice Harris and Amparo Crespo for their hard work and dedication.

Hot topics discussed

After lunch on Sunday, small groups gathered to discuss "hot topics" suggested by NPND members through a member survey conducted earlier in the year. Topics included the legislative process; rural and Native American issues; communication; fundraising; NPND 2000, a strategic planning program for NPND and the justice system's treatment of people with disabilities.

A wake-up call is sounded

On Monday, Oct. 3, NPND held its first congressional briefing, "The Reauthorization of IDEA: Parents' Perspectives." During the briefing, sponsored by the Senate Subcommittee on Disability Policy and the House Select Subcommittee on Education and Civil Rights, parent panels addressed critical issues in maintaining the rights and protections already embedded in IDEA. Many parents shared stories about the successful benefits of IDEA.

Panels included Parent Participation: The Key to Success; Least-Restrictive Environment; Procedural Safeguards; Equal Justice and Monitoring.

In addition to parents, Bobby Silverstein, chief of staff for the Senate Subcommittee on Disability Policy and Maria Cuprill, chief of staff for the House Select Subcommittee on Education and Civil Rights, gave compelling presentations about the magnitude of the upcoming fight to retain the protections children with disabilities now have to a free appropriate education.

The National Parent Network on Disabilities Board of Directors

Marta Anchondo
TASK, Anaheim, CA

Dianna Autin
Advocates for Children of New York, Long Island, NY

Margaret Burley
OCEHC, Marion, OH

Joanne Butts
Washington PAVE, Tacoma, WA, *President*

Connie Curtin
Vermont Parent Information Center, Burlington, VT

Diana Cuthbertson
Statewide Parent Advocacy Network (SPAN), Westfield, NJ, *Past President*

Joseph Garcia
Touchstones, Seattle, WA

Paula Goldberg
PACER Center, Minneapolis, MN

Connie Hawkins
Exceptional Children's Assistance Center (ECAC), Davidson, NC,

Bonnie Johnson
Arkansas Disabilities Coalition, Little Rock, AK

Joan Kilburn
MATRIX, A Parent Network & Resource Center, Mill Valley, CA, *Treasurer*

Sue Pratt
CAUSE, Lansing, MI

Pat Smith
Georgia/ARC, East Point, GA, *Parliamentarian*

Pam Steneberg
Disability Rights Education & Defense Fund (DREDF), Berkeley, CA, *Vice President*

Janet Vohs
Federation for Children with Special Needs, Boston, MA, *Secretary*

Patricia McGill Smith
Executive Director

1995 Annual Meeting Dates Set

Mark your calendars now! The next NPND Annual Meeting will be held on September 23–25, 1995. Contact NPND for more information.

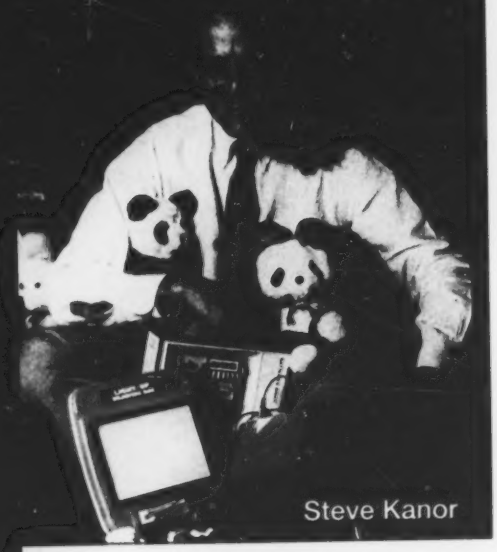
936

Toys for Special Children

The people of Toys for Special Children have sought to create a new world of play for the handicapped through the development of specially adapted toys, capability switches, activity centers, augmentative communication aids, and countless other special devices for the handicapped.

Vibrating Light

Call 800-832-8697


Steve Kanor

Special Service

We offer many standard technical solutions for handicapped people. We realize that for some, special adaptions are needed. Please call us so that we can discuss fabricating custom equipment for your special requirements.

"Dr. Kanor's devices have benefits beyond words"

-The New York Times-
Oct. 20th, 1991

A unique resource for technology which can be used to increase, maintain, or improve functional capabilities of individuals with disabilities.

The Cooper Car

To get your catalog call or write to:
Toys for Special Children
385 Warburton Avenue
Hasting-on-Hudson, NY 10706
800-832-8697

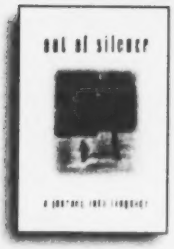
Circle # 194

EXCEPTIONAL PARENT *Library*

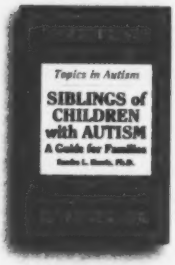
Parenting Your Child With a Disability

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

AUTISM



OUT OF SILENCE
A journey into language
RUSSELL MARTIN
A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.
HH083AM **$22.50**

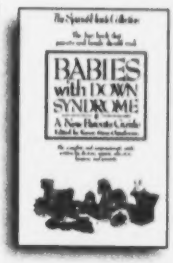


SIBLINGS OF CHILDREN WITH AUTISM
A Guide for Families
S.L. HARRIS, PH.D.
Understand sibling relationships, how autism affects them and what families can do to support their other children.
WB096AM **$12.95**

SON RISE
The Miracle Continues
BARRY N. KAUFMAN
An awe-inspiring reminder that love made tangible can move mountains.
01089AM **$20.00**

DOWN SYNDROME

ADVANCES IN DOWN SYNDROME
EDITED BY V. DMITRIEV & P. OELWEIN
Twenty experts contribute their recent research, experience, and thoughts on future directions for children with Down syndrome.
PE045DS **$31.00**

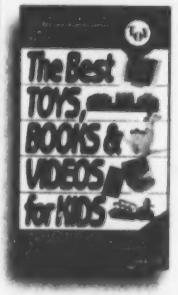


BABIES WITH DOWN SYNDROME
A Parents' Guide
ED. BY KAREN STRAY-GUNDERSEN
The complete guide for new parents of babies with Down Syndrome. Written by professionals and parents, this book covers everything new parents need to know.
WB010MR **$14.95**

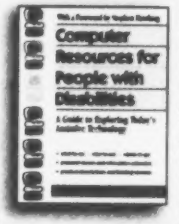
DOWN SYNDROME
A Resource Handbook
EDITED BY CAROL TINGEY
This book, written for both families and clinicians, is personal in approach and direct in style. It discusses with compassion and knowledge the genetic, medical, social, and family aspects of Down syndrome.
PE050DS **$22.00**

DISABILITY, GENERAL

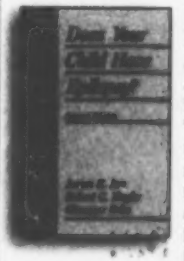
ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
TONI FLOWERS
Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels.
PE035OD **$29.00**



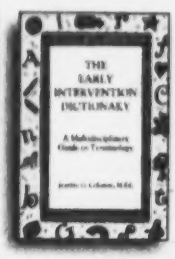
THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
HC082OD **$12.00**



COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES: ***A Guide to Exploring Today's Assistive Technology***
THE ALLIANCE FOR TECHNOLOGY ACCESS
Provides user-friendly support, information, and up-to-date answers.
HP087OD **$14.95**

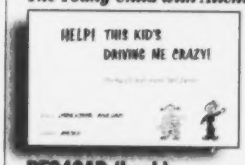


DOES YOUR CHILD HAVE EPILEPSY?
2nd Edition
JAMES E. JAN, ROBERT G. ZIEGLER AND GIUSEPPE ERBA
This book provides information on the most common seizures, causes, principles of treatment, investigation and outcome, with a wide range of helpful suggestions from infancy to early adulthood.
PE038OD **$22.00**



THE EARLY INTERVENTION DICTIONARY
A Multi-disciplinary Guide to Terminology
JEANINE COLEMAN, M.ED.
Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.
WB030EI **$16.95**

HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder



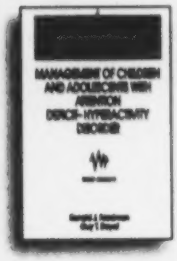
L. ADKINS & J. CADY
Information about typical behavior characteristics; suggestions on how to foster the development of appropriate behavior.
PE040AD (book) **$5.00**
PE040 (tape) **$89.00**

I AM, I CAN, I WILL
MISTER ROGERS
A series of audio and printed materials designed for young children with disabilities. These programs may be used to help develop a child's emotional, language, perceptual, listening and creative abilities.
15 tapes & 5 books
PE056OD **$119.00**

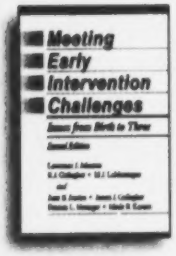
IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
EP001EP **$14.95**

THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
WB020OD **$14.95**

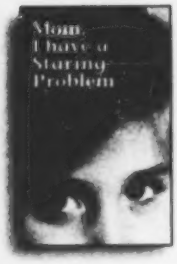
LITTLE CHILDREN, BIG NEEDS: ***Parents Discuss Raising Children with Exceptional Needs***
DON WEINHOUSE, PH.D. AND MARILYN WEINHOUSE, M.A.
What are the concerns of parents who raise disabled children? Contains candid interviews with 50 families of children with a wide range of disabilities.
RUP068OD **$12.95**



MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH ADHD
Third Edition
RONALD J. FRIEDMAN & GUY T. DOYAL
The most current medical and psychological research findings with 20 years' clinical experience. Written in a clear, nontechnical manner.
PE039AD **$24.00**



MEETING EARLY INTERVENTION CHALLENGES
Issues from Birth to Three, Second Edition
L.J. JOHNSON ET. AL.
Guiding professionals and parents through changes in early intervention practice.
PB095EJ **$30.00**

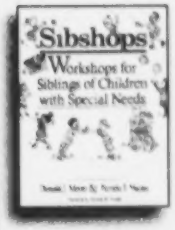


MOM, I HAVE A STARING PROBLEM
M.C. BUCKEL & T. BUCKEL
A true story of Petit Mal Seizures and the hidden problem it can cause: Learning Disability
MB097SZ **$3.95**
(Includes shipping charges)

A PARENT'S GUIDE TO MIDDLE EAR INFECTIONS
DORINNE S. DAVIS, MA, CCC-A
Answering questions about ear infections in understandable terms. Anatomy, physiology and coping at home and socially.
HY090OD **$24.95**

PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP0210D **$75.50**

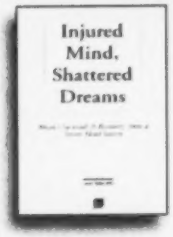
PLANNING FOR THE FUTURE
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP0240D **$24.95**



SIBSHOPS
Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB086OD **$32.00**

THAT ALL MAY WORSHIP
An Interfaith Welcome to People with Disabilities
GINNY THORNBURGH
An interfaith handbook to assist congregations in welcoming people with disabilities to promote acceptance and full participation.
ND084OD **$10.00**

INJURY



INJURED MINDS, SHATTERED DREAMS:
Brian's Survival from a Severe Head Injury
JANET MILLER RIFE
Recovery and victory a family can achieve through caring.
BL067OD **$17.95**

WHEN YOUNG CHILDREN ARE INJURED: ***Families as Caregivers in Hospitals and at Home***
J. HALTIWANGER & M. LASH
A book about the family's role in caregiving when a young child is injured.
EP085ML **$7.50**
(Includes shipping charges)

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$7.50**
(Includes shipping charges)

WHEN YOUR CHILD IS SERIOUSLY INJURED
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$4.50**
(Includes shipping charges)

CHILDREN'S BOOKS

JOEY AND SAM
I. KATZ & E. RITVO, M.D.
A heartwarming storybook about autism, a family, and a brother's love.
RL099AM **$9.95**

MY BUDDY
A. OSOFSKY
Buddy is the best dog a boy could have. Fully illustrated, this book demonstrates the desires of the disabled to be independent.
HH098CB **$5.95**

Mail to: **Exceptional Parent,** Dept. EP0412, P.O. Box 8045, Brick, N.J. 08723
Or call (800) 535-1910

QTY.	TITLES & ORDER NO.	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES: U.S. – $3.50 for 1 item; 75¢ for each additional item. Foreign – $6.50 for 1 item; 75¢ for each additional item.

Sub-Total	
NJ Residents add 6% Sales Tax	
Shipping	
TOTAL	

U.S. funds only. These prices are subject to change. Please allow 4-6 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas returns.

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

I have enclosed my check payable to Exceptional Parent or charge to my: ❑ Visa ❑ Mastercard

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date ____/____

Signature _____

933

Circle #300 to receive a brochure of the complete library

CHILDREN'S PAGE

IF I COULD GIVE THE WORLD A GIFT...

by Joshua W. Humphreys

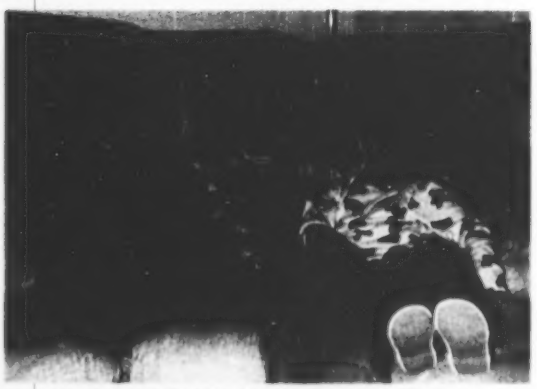
If I could give the world a gift, it would be what my brother has taught me:

My brother is patient all the time. He waits for me, even when I sometimes don't have time for him.

My brother is always happy and smiles with a big, open-mouth smile. He always gives me a smile, even when I don't feel like smiling or when I have had a bad day.

My brother doesn't care if I don't make straight A's or score a goal in soccer; he will always love me, no matter what.

Christmas 1992 with the Humphreys: [from left to right] Six-month-old Jarrett and older brothers, Joshua, 8, and Jordan, 6.



Jordan [right] "only knows to love," says older brother, Joshua [middle]. With them is younger brother, Jarrett.

My brother doesn't care what color you are or what you wear. He will love you whether you are young or old or rich or poor.

My brother will never know bad—only good. He will not know if someone is mean to him. He will not know about the bad things people do.

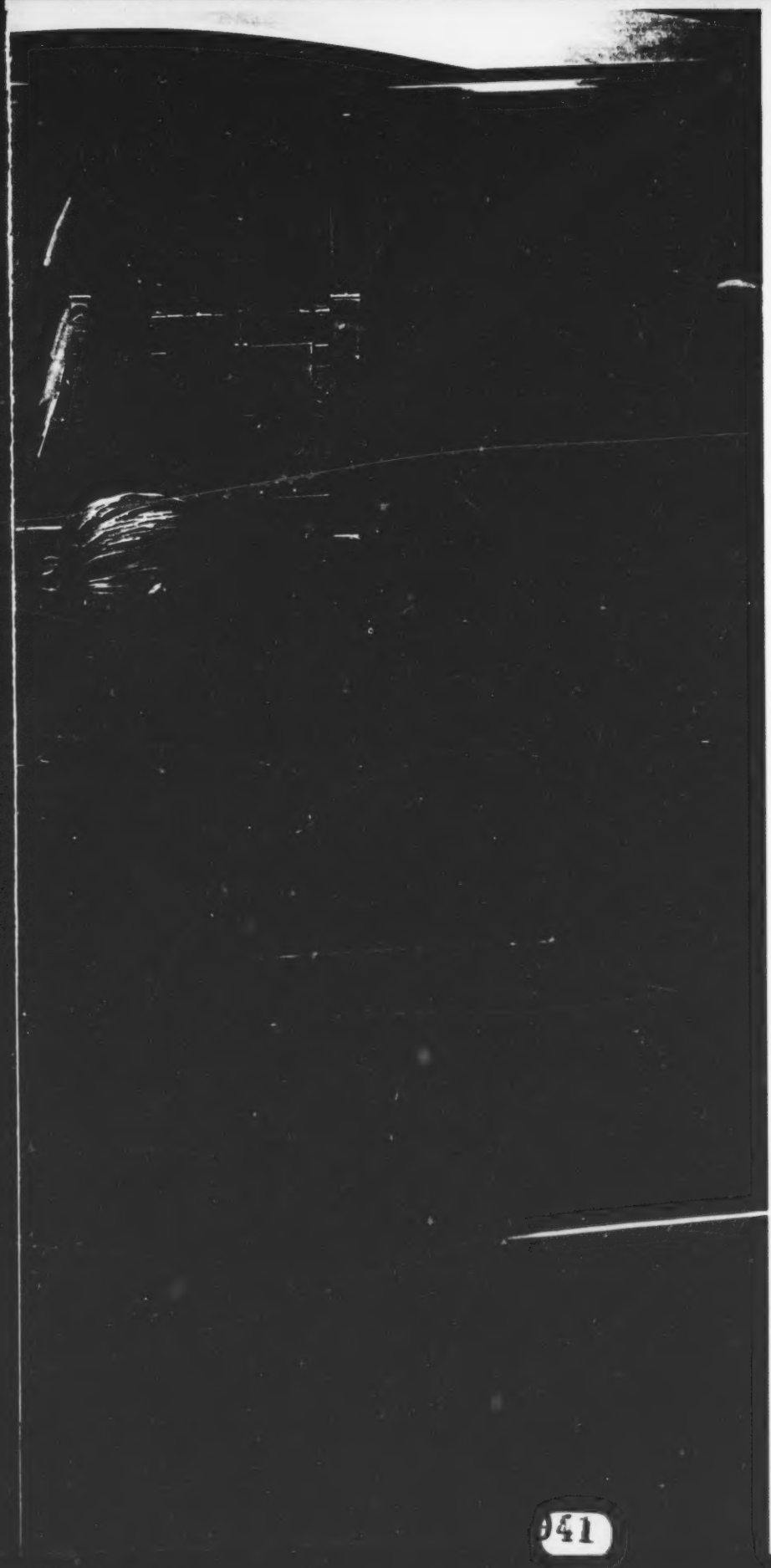
My brother has taught me so much, even though he has a mind and a body that don't work very well.

My brother only knows how to love, and this is how God wants us to be—the same way He loves us no matter what.

Joshua, 11, lives with his parents, Karen and Dennis, and his two brothers, Jordan and Jarrett, in Waco, Texas. Jordan, 8, has agenesis of the corpus callosum. Joshua, a fifth grader at Midway Intermediate School, entered this essay in a contest sponsored by the National PTA where it won first prize at the campus, council and district levels. Joshua's hobbies include drawing, soccer and golf.

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

940



HALF A LIFT IS *STILL* BETTER THAN WHOLE.

With maximum passenger seat maneuverability, a new easy off/on ground hugging platform, plus reliable all-electric operation.

The Crow River Industries VANGATER™ fold-in-half lift is a timeless classic. When folded it offers half a doorway of usable space for easy loading/unloading, more usable interior space, a clearer side view, and allows the front passenger seat to be almost fully reclined for maximum comfort. But we can't seem to stop trying to improve on perfection.

All-electric reliability.

The enclosed non-hydraulic, all-electric operating mechanism is cleaner and quieter than hydraulic lifts, especially in extreme temperatures. (There's also no leakage or unpleasant odor.) And our new auxiliary electric override provides emergency electrical lift power—not to mention peace of mind—when you need it most.

A flatter platform.

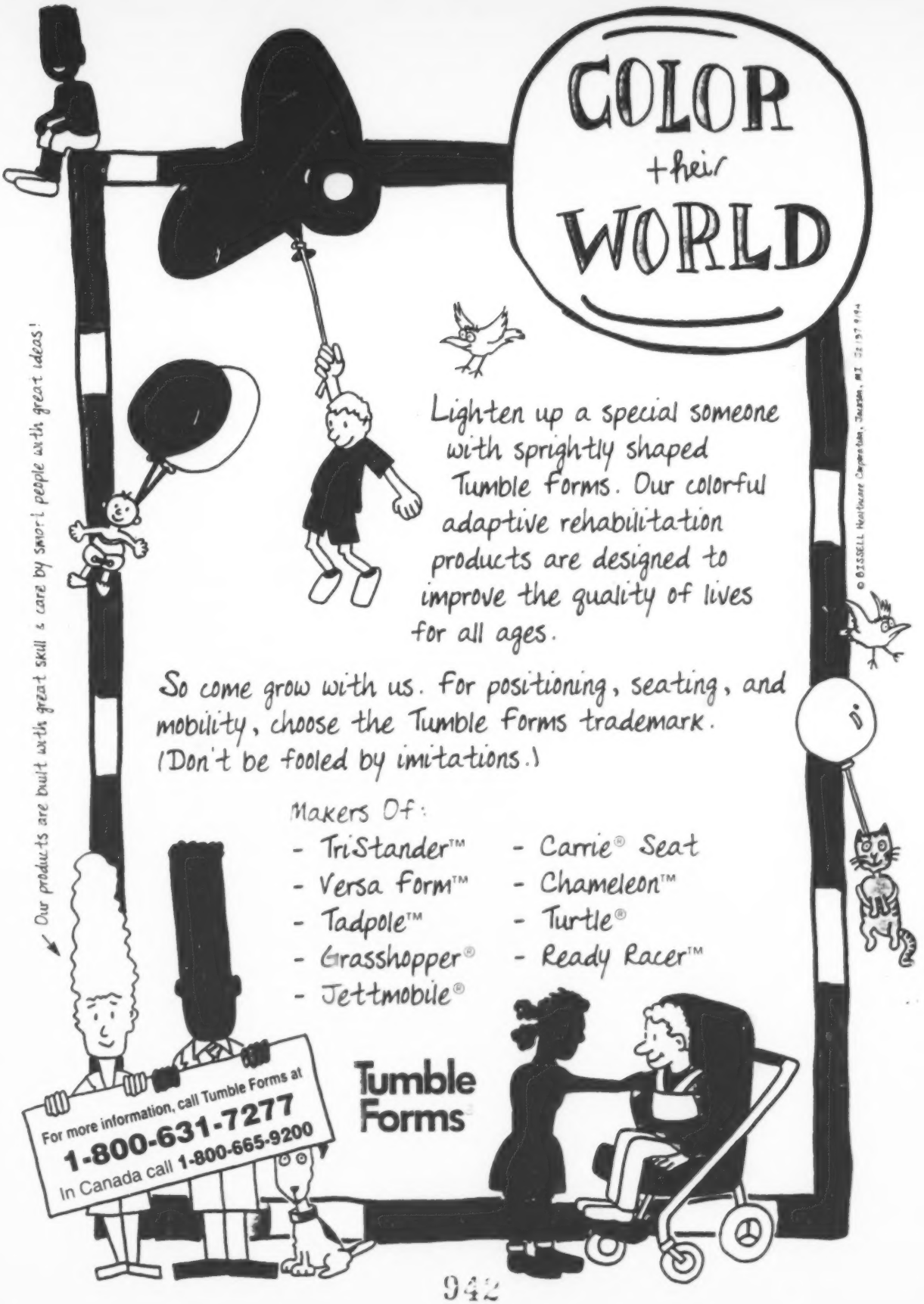
We've made getting on and off the VANGATER™ easier than ever with a new flatter platform that sacrifices nothing in ruggedness and reliability. And you'll find the improved side entry option and exit access great in tight parking situations!

RAPID RESPONSE LINE:
For more information and the name of your closest dealer call *today*:
1-800-488-7688

Circle # 14

CROW RIVER™
Industries Incorporated

14800 28th Avenue North
Minneapolis, MN 55447 (U.S.A.)
(In Minnesota, 612-559-1680)


COLOR
+their
WORLD
Lighten up a special someone with sprightly shaped Tumble Forms. Our colorful adaptive rehabilitation products are designed to improve the quality of lives for all ages.
So come grow with us. For positioning, seating, and mobility, choose the Tumble Forms trademark. (Don't be fooled by imitations.)
Makers Of:
- TriStander™
- Versa Form™
- Tadpole™
- Grasshopper®
- Jettmobile®
- Carrie® Seat
- Chameleon™
- Turtle®
- Ready Racer™
Tumble Forms
For more information, call Tumble Forms at
1-800-631-7277
In Canada call 1-800-665-9200
Our products are built with great skill & care by smart people with great ideas!
© BISSELL Healthcare Corporation, Jackson, MI

Circle # 7